hcpc health & care professions council

Standards of proficiency

Practitioner psychologists

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Foreword

We are pleased to present the Health and Care Professions Council's (HCPC) standards of proficiency for practitioner psychologists.

We first published standards of proficiency for practitioner psychologists in July 2009. We made minor changes to the standards following publication in October 2010. We review the standards regularly to look at how they are working and to check whether they continue to reflect current practice in the professions we regulate.

These new revised standards are a result of our most recent review of the standards of proficiency. As a result of the first stage of the review, and the results of a public consultation, we have revised our generic standards which apply to all the professions we regulate. The revised standards are now based around 15 generic statements. This new structure means that we can retain the standards which are shared across all the professions we regulate, whilst allowing us more flexibility in describing the detailed standards which are specific to individual professions.

The profession-specific standards for practitioner psychologists included in this document were developed through the input of the relevant professional bodies and the views of all stakeholders during a further public consultation. The review process and consultation produced valuable feedback and we are grateful to all those who gave their time to help us in shaping the new standards.

We have made a small number of changes to the standards overall, mainly to reflect developments in education and practice, to clarify our intentions and to correct any errors or omissions. We have also made some minor changes to the introduction, in particular to explain the language we use in the standards.

We are confident that the standards are fit for purpose and reflect safe and effective professional practice for practitioner psychologists.

These standards are effective from Wednesday 1 July 2015.

Introduction

This document sets out the standards of proficiency. These standards set out safe and effective practice in the professions we regulate. They are the threshold standards we consider necessary to protect members of the public. They set out what a student must know, understand and be able to do by the time they have completed their training, so that they are able to register with us. Once on our Register you must meet those standards of proficiency which relate to the areas in which you work.

We also expect you to keep to our standards of conduct, performance and ethics and standards for continuing professional development. We publish these in separate documents, which you can find on our website.

In the practitioner psychologist part of our Register, there are seven distinct domains. The standards of proficiency in this document include both generic elements, which apply to all our registrants, profession-specific elements which are relevant to all practitioner psychologists and domain-specific standards which apply to a particular domain. The generic standards are written in **bold**, the profession-specific standards are written in plain text, with the domain-specific standards written in plain blue text.

We have numbered the standards so that you can refer to them more easily. The standards are not hierarchical and are all equally important for practice.

A note about our expectations of you

You must meet all the standards of proficiency to register with us and meet the standards relevant to your scope of practice to stay registered with us.

It is important that you read and understand this document. If your practice is called into question we will consider these standards (and our standards of conduct, performance and ethics) in deciding what action, if any, we need to take.

The standards set out in this document complement information and guidance issued by other organisations, such as your professional body or your employer. We recognise the valuable role played by professional bodies in providing guidance and advice about good practice which can help you to meet the standards in this document.

Your scope of practice

Your scope of practice is the area or areas of your profession in which you have the knowledge, skills and experience to practise lawfully, safely and effectively, in a way that meets our standards and does not pose any danger to the public or to yourself.

We recognise that a registrant's scope of practice will change over time and that the practice of experienced registrants often becomes more focused and specialised than that of newly registered colleagues. This might be because of specialisation in a certain area or with a particular client group, or a movement into roles in management, education or research. Every time you renew your registration, you will be asked to sign a declaration that you continue to meet the standards of proficiency that apply to your scope of practice.

Your particular scope of practice may mean that you are unable to continue to demonstrate that you meet all of the standards that apply for the whole of your profession. As long as you make sure that you are practising safely and effectively within your given scope of practice and do not practise in the areas where you are not proficient to do so, this will not be a problem. If you want to move outside of your scope of practice, you should be certain that you are capable of working lawfully, safely and effectively. This means that you need to exercise personal judgement by undertaking any necessary training and experience, before moving into a new area of practice.

Meeting the standards

It is important that you meet our standards and are able to practise lawfully, safely and effectively. However, we do not dictate how you should meet our standards. There is normally more than one way in which each standard can be met and the way in which you meet our standards might change over time because of improvements in technology or changes in your practice.

We often receive questions from registrants who are concerned that something they have been asked to do, a policy, or the way in which they work might mean they cannot meet our standards. They are often worried that this might have an effect on their registration.

As an autonomous professional, you need to make informed, reasoned decisions about your practice to ensure that you meet the standards that apply to you. This includes seeking advice and support from education providers, employers, colleagues, professional bodies, unions and others to ensure that the wellbeing of service users is safeguarded at all times. So long as you do this and can justify your decisions if asked to, it is very unlikely that you will not meet our standards.

Language

We recognise that our registrants work in a range of different settings, which include clinical practice, education, research and roles in industry. We also recognise that the use of terminology can be an emotive issue.

Our registrants work with very different people and use different terms to describe the groups that use, or are affected by, their services. Some of our registrants work with patients, some with clients which can include organisations, and others with service users. We have used the term ‘service user’ in a broad sense in the standards to refer to anyone who uses or is affected by the services of our registrants. However, the term you use to describe the groups that use, or are affected by, the services you offer will be guided by context and the area or domain you practise in.

When we consulted on the standards we received a lot of different feedback about our use of the terms 'evidence-based' and 'evidence-informed' but with no clear consensus on which of these terms were preferred. These terms are about practitioner psychologists' awareness and use of research and other evidence, where this is available, to guide their practice. As a result, in standard 12.1, which applies to all practitioner psychologists and is about use of evidence more generally, we have used both terms. In the other standards which apply to specific psychological models or frameworks, we have retained our existing terminology of 'evidence-based'.

In the standards of proficiency, we use phrases such as 'understand', 'know', and 'be able to'. This is so the standards remain applicable to current registrants in maintaining their fitness to practise, as well as prospective registrants who have not yet started practising and are applying for registration for the first time.

These standards may change in the future

We have produced these standards after speaking to our stakeholders and holding a formal public consultation.

We will continue to listen to our stakeholders and will keep our standards under continual review. Therefore, we may make further changes in the future to take into account changes in practice.

We will always publicise any changes to the standards that we make by, for instance, publishing notices on our website and informing professional bodies.

Standards of proficiency

Registrant practitioner psychologists must:

1 be able to practise safely and effectively within their scope of practice

1.1 know the limits of their practice and when to seek advice or refer to another professional

1.2 recognise the need to manage their own workload and resources effectively and be able to practise accordingly

2 be able to practise within the legal and ethical boundaries of their profession

2.1 understand the need to act in the best interests of service users at all times

2.2 understand what is required of them by the Health and Care Professions Council

2.3 understand the need to respect and uphold the rights, dignity, values and autonomy of service users including their role in the assessment, treatment and intervention process and in maintaining health and wellbeing

2.4 recognise that relationships with service users should be based on mutual respect and trust, and be able to maintain high standards of practice even in situations of personal incompatibility

2.5 understand current legislation applicable to the work of their profession

2.6 understand the importance of and be able to obtain informed consent

2.7 be able to exercise a professional duty of care

2.8 understand the complex ethical and legal issues of any form of dual relationship and the impact these may have on service users

2.9 understand the power imbalance between practitioners and service users and how this can be managed appropriately

2.10 be able to recognise appropriate boundaries and understand the dynamics of power relationships

2.11 understand the organisational context for their practice as a practitioner psychologist

3 be able to maintain fitness to practise

3.1 understand the need to maintain high standards of personal and professional conduct

3.2 understand the importance of maintaining their own health

3.3 understand both the need to keep skills and knowledge up to date and the importance of career-long learning

3.4 be able to manage the physical, psychological and emotional impact of their practice

4 be able to practise as an autonomous professional, exercising their own professional judgement

4.1 be able to assess a professional situation, determine the nature and severity of the problem and call upon the required knowledge and experience to deal with the problem

4.2 be able to make reasoned decisions to initiate, continue, modify or cease treatment, intervention or the use of techniques or procedures, and record the decisions and reasoning appropriately

4.3 be able to initiate resolution of problems and be able to exercise personal initiative

4.4 recognise that they are personally responsible for and must be able to justify their decisions

4.5 be able to make and receive appropriate referrals

4.6 understand the importance of participation in training, supervision and mentoring

5 be aware of the impact of culture, equality and diversity on practice

5.1 understand the impact of differences such as gender, sexuality, ethnicity, culture, religion and age on psychological wellbeing or behaviour

5.2 understand the requirement to adapt practice to meet the needs of different groups and individuals

6 be able to practise in a non-discriminatory manner

7 understand the importance of and be able to maintain confidentiality

7.1 be aware of the limits of the concept of confidentiality

7.2 understand the principles of information governance and be aware of the safe and effective use of health, social care and other relevant information

7.3 be able to recognise and respond appropriately to situations where it is necessary to share information to safeguard service users or the wider public

8 be able to communicate effectively

8.1 be able to demonstrate effective and appropriate verbal and non-verbal skills in communicating information, advice, instruction and professional opinion to service users, colleagues and others

8.2 be able to communicate in English to the standard equivalent to level 7 of the International English Language Testing System, with no element below 6.5[1]

8.3 understand how communication skills affect assessment of, and engagement with, service users and how the means of communication should be modified to address and take account of factors such as age, capacity, learning ability and physical ability

8.4 be able to select, move between and use appropriate forms of verbal and non-verbal communication with service users and others

8.5 be aware of the characteristics and consequences of verbal and non-verbal communication and how this can be affected by factors such as age, culture, ethnicity, gender, socio-economic status and spiritual or religious beliefs

[1] The International English Language Testing System (IELTS) tests competence in the English language. Applicants who have qualified outside of the UK, whose first language is not English and who are not nationals of a country within the European Economic Area (EEA) or Switzerland, must provide evidence that they have reached the necessary standard. Please visit our website for more information.

8.6 understand the need to provide service users or people acting on their behalf with the information necessary to enable them to make informed decisions

8.7 be able to select the appropriate means for communicating feedback to service users

8.8 be able to provide psychological opinion and advice in formal settings, as appropriate

8.9 be able to communicate ideas and conclusions clearly and effectively to specialist and non-specialist audiences

8.10 be able to explain the nature and purpose of specific psychological techniques to service users

8.11 be able to summarise and present complex ideas in an appropriate form

8.12 understand the need to assist the communication needs of service users such as through the use of an appropriate interpreter, wherever possible

8.13 recognise the need to use interpersonal skills to encourage the active participation of service users

8.14 be able to use formulations to assist multi-professional communication and understanding

8.15 understand explicit and implicit communications in a practitioner – service user relationship

8.16 be able to appropriately define and contract work with commissioning service users or their representatives

Counselling psychologists only

8.17 understand how empathic understanding can be helped by creativity and artistry in the use of language and metaphor

9 be able to work appropriately with others

9.1 be able to work, where appropriate, in partnership with service users, other professionals, support staff and others

9.2 understand the need to build and sustain professional relationships as both an independent practitioner and collaboratively as a member of a team

9.3 understand the need to engage service users and carers in planning and evaluating assessments, treatments and interventions to meet their needs and goals

9.4 understand the need to implement interventions, care plans or management plans in partnership with service users, other professionals and carers

9.5 be able to initiate, develop and end a practitioner – service user relationship

9.6 understand the dynamics present in relationships between service users and practitioners

9.7 be able to contribute effectively to work undertaken as part of a multi-disciplinary team

9.8 be able to plan, design and deliver teaching and training which takes into account the needs and goals of participants

9.9 be able to support the learning of others in the application of psychological skills, knowledge, practices and procedures

9.10 be able to use psychological formulations with service users to facilitate their understanding of their experience or situation

10 be able to maintain records appropriately

10.1 be able to keep accurate, comprehensive and comprehensible records in accordance with applicable legislation, protocols and guidelines

10.2 recognise the need to manage records and all other information in accordance with applicable legislation, protocols and guidelines

11 be able to reflect on and review practice

11.1 understand the value of reflection on practice and the need to record the outcome of such reflection

11.2 recognise the value of case conferences or other methods of review

11.3 be able to reflect critically on their practice and consider alternative ways of working

11.4 understand models of supervision and their contribution to practice

Counselling psychologists only

11.5 be able to critically reflect on the use of self in the therapeutic process

12 be able to assure the quality of their practice

12.1 be able to engage in evidence-based and evidence-informed practice, evaluate practice systematically and participate in audit procedures

12.2 be able to gather information, including qualitative and quantitative data, that helps to evaluate the responses of service users to their care or experience

12.3 be aware of the role of audit and review in quality management, including quality control, quality assurance and the use of appropriate outcome measures

12.4 be able to maintain an effective audit trail and work towards continual improvement

12.5 be aware of, and able to participate in, quality assurance programmes, where appropriate

12.6 be able to evaluate intervention plans using recognised outcome measures and revise the plans as necessary in conjunction with the service user

12.7 be able to revise formulations in the light of ongoing intervention and when necessary reformulate the problem

12.8 recognise the need to monitor and evaluate the quality of practice and the value of contributing to the generation of data for quality assurance and improvement programmes

12.9 be able to monitor agreements and practices with service users, groups and organisations

13 understand the key concepts of the knowledge base relevant to their profession

13.1 understand the structure and function of the human body, together with knowledge of health, well-being, disease, disorder and dysfunction relevant to their domain

13.2 be aware of the principles and applications of scientific enquiry, including the evaluation of the effectiveness of interventions and the research process

13.3 recognise the role of other professions and stakeholders relevant to the work of their domain

13.4 understand the structures and functions of UK service providers applicable to the work of their domain

13.5 understand the theoretical basis of, and the variety of approaches to, assessment and intervention

13.6 understand the role of the practitioner psychologist across a range of settings and services

13.7 understand the concept of leadership and its application to practice

13.8 understand the application of consultation models to service-delivery and practice, including the role of leadership and group processes

Clinical psychologists only

13.9 understand theories and evidence concerning psychological development and psychological difficulties across the lifespan and their assessment and remediation

13.10 understand more than one evidence-based model of formal psychological therapy

13.11 understand psychological models related to how biological, sociological and circumstantial or life-event-related factors impinge on psychological processes to affect psychological wellbeing

13.12 understand psychological models related to a range of presentations including:

- service users with presentations from acute to enduring and mild to severe;
- problems with biological or neuropsychological aspects; and
- problems with mainly psychosocial factors including problems of coping, adaptation and resilience to adverse circumstances and life events, including bereavement and other chronic physical and mental health conditions

13.13 understand psychological models related to service users:

- from a range of social and cultural backgrounds;
- of all ages;
- across a range of intellectual functioning;
- with significant levels of challenging behaviour;
- with developmental learning disabilities and cognitive impairment;
- with communication difficulties;
- with substance misuse problems; and
- with physical health problems

13.14 understand psychological models related to working:

- with service users, couples, families, carers, groups and at the organisational and community level; and
- in a variety of settings including in-patient or other residential facilities with high-dependency needs, secondary health care and community or primary care

13.15 understand change and transition processes at the individual, group and organisational level

13.16 understand social approaches such as those informed by community, critical and social constructivist perspectives

13.17 understand the impact of psychopharmacological and other clinical interventions on psychological work with service users

Counselling psychologists only

13.18 understand the philosophical bases which underpin those psychological theories which are relevant to counselling psychology

13.19 understand the philosophy, theory and practice of more than one evidence-based model of formal psychological therapy

13.20 understand psychological models related to a range of presentations including:

- service users with presentations from acute to enduring and mild to severe;
- problems with biological or neuropsychological aspects; and
- problems with mainly psychosocial factors including problems of coping, adaptation and resilience to adverse circumstances and life events, including bereavement and other chronic physical and mental health conditions

13.21 understand the therapeutic relationship and alliance as conceptualised by each model

13.22 understand the spiritual and cultural traditions relevant to counselling psychology

13.23 understand the primary philosophical paradigms that inform psychological theory with particular regard to their relevance to, and impact upon, the understanding of the subjectivity and inter-subjectivity of experience throughout human development

13.24 understand theories of human cognitive, emotional, behavioural, social and physiological functioning relevant to counselling psychology

13.25 understand different theories of lifespan development

13.26 understand social and cultural contexts and the nature of relationships throughout the lifespan

13.27 understand theories of psychopathology and of change

13.28 understand the impact of psychopharmacology and other interventions on psychological work with service users

Educational psychologists only

13.29 understand the role of the educational psychologist across a range of school and community settings and services

13.30 understand the educational and emotional factors that facilitate or impede the provision of effective teaching and learning

13.31 understand psychological theories of, and research evidence in, child, adolescent and young adult development relevant to educational psychology

13.32 understand the structures and systems of a wide range of settings in which education, health and care are delivered for children, adolescents and young adults, including child protection procedures

13.33 understand psychological models related to the influence of school ethos and culture, educational curricula, communication systems, management and leadership styles on the cognitive, behavioural, emotional and social development of children, adolescents and young adults

13.34 understand psychological models of the factors that lead to underachievement, disaffection and social exclusion amongst vulnerable groups

13.35 understand theories and evidence underlying psychological intervention with children, adolescents, young adults, their parents or carers, and education and other professionals

13.36 understand psychological models related to the influence on development of children, adolescents and young adults from:

- family structures and processes;
- cultural and community contexts; and
- organisations and systems

13.37 understand change and transition processes at the individual, group and organisational level

13.38 understand the theoretical basis of, and the variety of approaches to, consultation and assessment in educational psychology

Forensic psychologists only

13.39 understand the application of psychology in the legal system

13.40 understand the application and integration of a range of theoretical perspectives on socially and individually damaging behaviours, including psychological, social and biological perspectives

13.41 understand psychological models related to a range of presentations including:

- service users with presentations from acute to enduring and mild to severe;
- problems with biological or neuropsychological aspects; and
- problems with mainly psychosocial factors including problems of coping, adaptation and resilience to adverse circumstances and life events, including bereavement and other chronic physical and mental health conditions

13.42 understand psychological theories and their application to the provision of psychological therapies that focus on offenders and victims of offences

13.43 understand effective assessment approaches with service users presenting with individually or socially damaging behaviour

13.44 understand the development of criminal and antisocial behaviour

13.45 understand the psychological interventions related to different service user groups including victims of offences, offenders, litigants, appellants and individuals seeking arbitration and mediation

Health psychologists only

13.46 understand context and perspectives in health psychology

13.47 understand the epidemiology of health and illness

13.48 understand:

- biological mechanisms of health and disease;
- health-related cognitions and behaviour;
- stress, health and illness;
- individual differences in health and illness;
- lifespan, gender and cross-cultural perspectives; and
- long-term conditions and disability

13.49 understand applications of health psychology and professional issues

13.50 understand healthcare in professional settings

Occupational psychologists only

13.51 understand the following in occupational psychology:

- human-machine interaction;
- design of environments and work;
- personnel selection and assessment;
- performance appraisal and career development;
- counselling and personal development;
- training;
- employee relations and motivation; and
- organisational development and change

Sport and exercise psychology

13.52 understand cognitive processes, including motor skills, practice skills, learning and perception; and self-regulation

13.53 understand psychological skills such as:

- goal setting;
- self-talk;
- imagery;
- pre-performance routines;
- arousal control, such as relaxation and activation; and
- strategies for stress and emotion management

13.54 understand exercise and physical activity including:

- determinants, such as motives, barriers and adherence;
- outcomes in relation to affect, such as mood and emotion;
- cognition and mental health issues, such as self-esteem, eating disorders, depression and exercise dependence;
- lifestyle and quality of life; and
- injury

13.55 understand individual differences including:

- mental toughness, hardiness and resilience;
- personality;
- confidence;
- motivation;
- self-concept and self-esteem; and
- stress and coping

13.56 understand social processes within sport and exercise psychology including:

- interpersonal skills and relationships;
- group dynamics and functioning;
- organisational issues; and
- leadership

13.57 understand the impact of developmental processes, including lifespan issues and processes related to career transitions and termination

14 be able to draw on appropriate knowledge and skills to inform practice

14.1 be able to apply psychology across a variety of different contexts using a range of evidence-based and theoretical models, frameworks and psychological paradigms

14.2 be able to change their practice as needed to take account of new developments or changing contexts

14.3 be able to conduct appropriate assessment or monitoring procedures, treatment, interventions, therapy or other actions safely and effectively

14.4 be able to conduct consultancy

14.5 be able to formulate specific and appropriate management plans including the setting of timescales

14.6 be able to manage resources to meet timescales and agreed project objectives

14.7 be able to use psychological formulations to plan appropriate interventions that take the service user's perspective into account

14.8 be able to direct the implementation of applications and interventions carried out by others

14.9 be able to gather appropriate information

14.10 be able to make informed judgements on complex issues in the absence of complete information

14.11 be able to work effectively whilst holding alternative competing explanations in mind

14.12 be able to generalise and synthesise prior knowledge and experience in order to apply them critically and creatively in different settings and novel situations

14.13 be able to select and use appropriate assessment techniques

14.14 be able to undertake and record a thorough, sensitive and detailed assessment, using appropriate techniques and equipment

14.15 be able to choose and use a broad range of psychological assessment methods, appropriate to the service user, environment and the type of intervention likely to be required

14.16 be able to decide how to assess, formulate and intervene psychologically from a range of possible models and modes of intervention with service users or service systems

14.17 be able to use formal assessment procedures, systematic interviewing procedures and other structured methods of assessment relevant to their domain

14.18 be able to undertake or arrange investigations as appropriate

14.19 be able to analyse and critically evaluate the information collected

14.20 be able to critically evaluate risks and their implications

14.21 be able to demonstrate a logical and systematic approach to problem solving

14.22 be able to use research, reasoning and problem solving skills to determine appropriate actions

14.23 be able to recognise when further intervention is inappropriate, or unlikely to be helpful

14.24 recognise the value of research to the critical evaluation of practice

14.25 be aware of a range of research methodologies

14.26 be able to evaluate research and other evidence to inform their own practice

14.27 be able to initiate, design, develop, conduct and critically evaluate psychological research

14.28 understand a variety of research designs

14.29 be able to understand and use applicable techniques for research and academic enquiry, including qualitative and quantitative approaches

14.30 be able to use professional and research skills in work with service users based on a scientist-practitioner and reflective-practitioner model that incorporates a cycle of assessment, formulation, intervention and evaluation

14.31 understand research ethics and be able to apply them

14.32 be able to conduct service and large scale evaluations

14.33 be able to use information and communication technologies appropriate to their practice

Clinical psychologists only

14.34 be able to assess social context and organisational characteristics

14.35 be able to develop psychological formulations using the outcomes of assessment, drawing on theory, research and explanatory models

14.36 be able to draw on knowledge of developmental, social and neuropsychological processes across the lifespan to facilitate adaptability and change in individuals, groups, families, organisations and communities

14.37 understand therapeutic techniques and processes as applied when working with a range of individuals in distress including:

- those who experience difficulties related to anxiety, mood, adjustment to adverse circumstances or life-events, eating, psychosis, use of substances; and
- those with somatoform, psychosexual, developmental, personality, cognitive and neurological presentations

14.38 be able, on the basis of psychological formulation, to implement psychological therapy or other interventions appropriate to the presenting problem and to the psychological and social circumstances of the service user

14.39 be able to implement therapeutic interventions based on a range of evidence-based models of formal psychological therapy, including the use of cognitive behavioural therapy

14.40 be able to promote awareness of the actual and potential contribution of psychological services

14.41 be able to evaluate and respond to organisational and service delivery changes, including the provision of consultation

Counselling psychologists only

14.42 be able to contrast, compare and critically evaluate a range of models of therapy

14.43 be able to draw on knowledge of developmental, social and neuropsychological processes across the lifespan to facilitate adaptability and change in individuals, groups, families, organisations and communities

14.44 be able to critically evaluate theories of mind and personality

14.45 understand therapy through their own life-experience

14.46 be able to adapt practice to take account of the nature of relationships throughout the lifespan

14.47 be able to formulate service users' concerns within the chosen therapeutic models

14.48 be able to critically evaluate psychopharmacology and its effects from research and practice

14.49 be able to critically evaluate theories of psychopathology and change

14.50 be able, on the basis of psychological formulation, to implement psychological therapy or other interventions appropriate to the presenting problem and to the psychological and social circumstances of the service user

14.51 be able to implement therapeutic interventions based on a range of evidence-based models of formal psychological therapy

14.52 be able to promote awareness of the actual and potential contribution of psychological services

14.53 be able to evaluate and respond to organisational and service delivery changes, including the provision of consultation

Educational psychologists only

14.54 be able to develop psychological formulations using the outcomes of assessment, drawing on theory, research and explanatory models

14.55 be able to carry out and analyse large-scale data gathering, including questionnaire surveys

14.56 be able to work with key partners to support the design, implementation, conduct, evaluation and dissemination of research activities and to support evidence-based research

14.57 be able to formulate interventions that focus on applying knowledge, skills and expertise to support local and national initiatives

14.58 be able to develop and apply effective interventions to promote psychological wellbeing, social, emotional and behavioural development and to raise educational standards

14.59 be able to implement interventions and plans through and with other professions and with parents or carers

14.60 be able to adopt a proactive and preventative approach in order to promote the psychological wellbeing of service users

14.61 be able to choose and use a broad range of psychological interventions, appropriate to the service user's needs and setting

14.62 be able to integrate and implement therapeutic approaches based on a range of evidence-based psychological interventions

14.63 be able to promote awareness of the actual and potential contribution of psychological services

Forensic psychologists only

14.64 be able to plan and design training and development programmes

14.65 be able to plan and implement assessment procedures for training programmes

14.66 be able to promote awareness of the actual and potential contribution of psychological services

14.67 be able to assess social context and organisational characteristics

14.68 be able to research and develop psychological methods, concepts, models, theories and instruments in forensic psychology

14.69 be able to evaluate and respond to organisational and service delivery changes, including the provision of consultation

14.70 be able to draw on knowledge of developmental and social changes and constraints across an individual's lifespan to facilitate adaptability and change

14.71 be able to implement interventions and care-plans through and with other professionals who form part of the service user care-team

14.72 be able, on the basis of empirically derived psychological formulation, to implement psychological therapy or other interventions appropriate to the presenting maladaptive or socially damaging behaviour of the service user

14.73 be able to integrate and implement evidence-based psychological therapy at either an individual or group level

Health psychologists only

14.74 be able to plan and implement assessment procedures for training programmes

14.75 be able to develop appropriate psychological assessments based on appraisal of the influence of the biological, social and environmental context

14.76 be able to develop psychological formulations using the outcomes of assessment, drawing on theory, research and explanatory models

14.77 be able to carry out and analyse large-scale data gathering, including questionnaire surveys

14.78 be able to draw on knowledge of developmental, social and biological processes across the lifespan to facilitate adaptability and change in individuals, groups, families, organisations and communities

14.79 be able to contrast, compare and critically evaluate a range of models of behaviour change

14.80 understand techniques and processes as applied when working with different individuals who experience difficulties

14.81 be able to develop and apply effective interventions to promote psychological wellbeing, social, emotional and behavioural development and to raise educational standards

14.82 be able to evaluate and respond to change in health psychology and in consultancy and service-delivery contexts

14.83 be able, on the basis of psychological formulation, to implement psychological therapy or other interventions appropriate to the presenting problem, and to the psychological and social circumstances of the service user

14.84 be able to integrate and implement therapeutic approaches based on a range of evidence-based psychological interventions

14.85 be able to choose and use a broad range of psychological interventions, appropriate to the service user's needs and setting

Occupational psychologists only

14.86 be able to assess individuals, groups and organisations in detail

14.87 be able to use the consultancy cycle

14.88 be able to research and develop psychological methods, concepts, models, theories and instruments in occupational psychology

14.89 be able to use psychological theory to guide research solutions for the benefit of organisations and individuals

14.90 understand and be able to act and provide advice on policy development concerning employees' and job seekers' rights

14.91 be able to run, direct, train and monitor others in the effective implementation of an application

Sport and exercise psychologists only

14.92 be able to assess social context and organisational characteristics

14.93 be able to develop psychological formulations using the outcomes of assessment, drawing on theory, research and explanatory models

14.94 be able to formulate service users' concerns within the chosen intervention models

15 understand the need to establish and maintain a safe practice environment

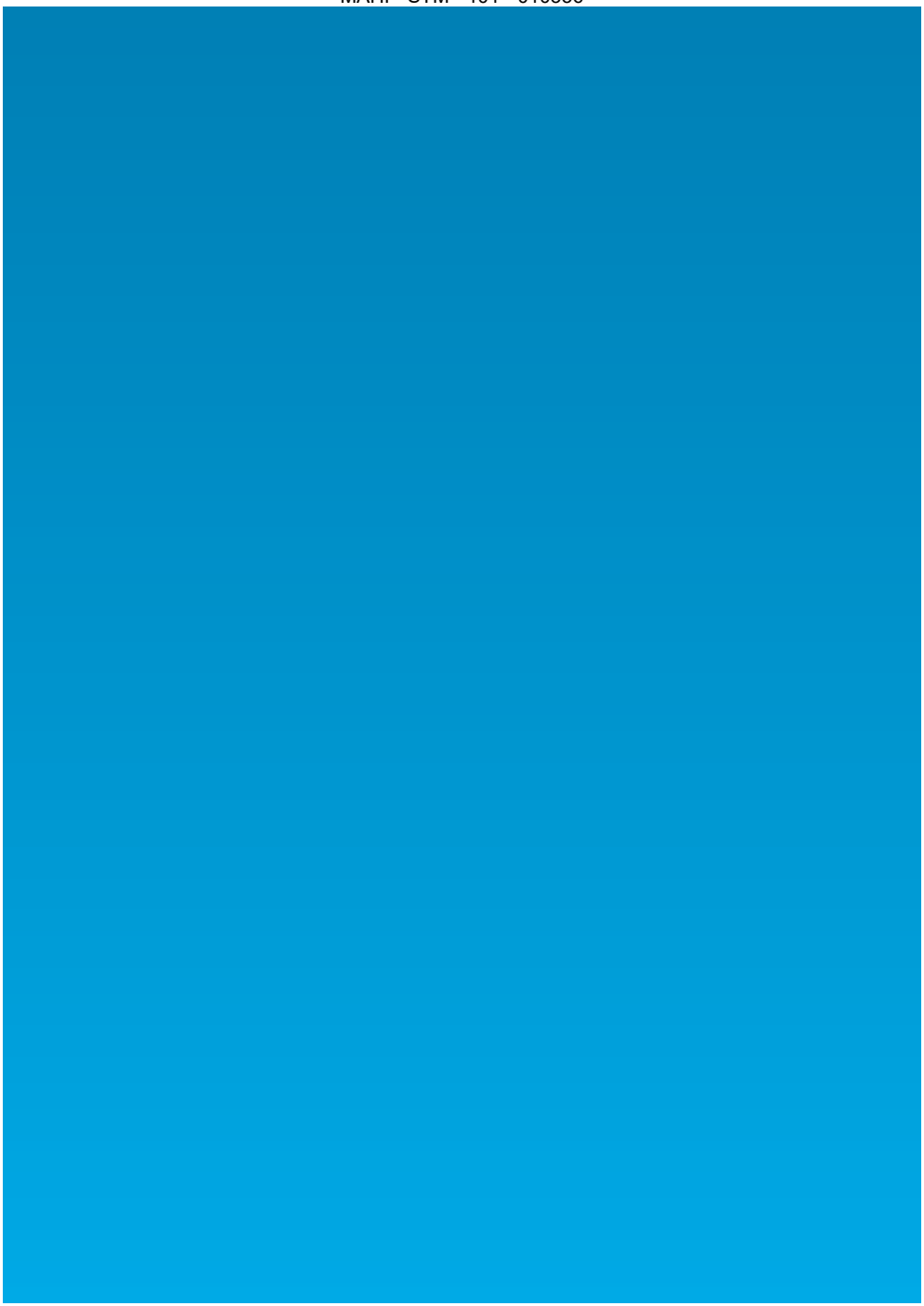
15.1 understand the need to maintain the safety of both service users and those involved in their care or experience

15.2 be aware of applicable health and safety legislation, and any relevant safety policies and procedures in force at the workplace, such as incident reporting, and be able to act in accordance with these

15.3 be able to establish safe environments for practice, which minimise risks to service users, those treating them and others

Sport and exercise psychologists only

15.4 be aware of the possible physical risks associated with certain sport and exercise contexts



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hcpc health & care professions council

Your duties as a registrant

Standards of conduct, performance and ethics

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Registrants must:

- promote and protect the interests of service users and carers;
- communicate appropriately and effectively;
- work within the limits of their knowledge and skills;
- delegate appropriately;
- respect confidentiality;
- manage risk;
- report concerns about safety;
- be open when things go wrong;
- be honest and trustworthy; and
- keep records of their work.

Introduction

About us

We are the Health and Care Professions Council (HCPC), a regulator set up to protect the public. To do this, we keep a register of professionals who meet our standards for their professional skills, knowledge and behaviour. The people on our register are referred to as 'registrants'.

About this document

This document sets out the standards of conduct, performance and ethics. The standards set out, in general terms, how we expect registrants to behave.

We currently regulate the following 15 professions.

- Arts therapists
- Biomedical scientists
- Chiropodists / podiatrists
- Clinical scientists
- Dietitians
- Hearing aid dispensers
- Occupational therapists
- Operating department practitioners
- Orthoptists
- Paramedics
- Physiotherapists
- Practitioner psychologists
- Prosthetists / orthotists
- Radiographers
- Speech and language therapists

Our registrants work in a range of different settings, which include direct practice, management, education, research and roles in industry. They also work with a variety of different people, including patients, clients, carers and other professionals.

In this document we have tried to use terms which everyone can understand. Some terms which have a specific meaning in this guide are explained in the glossary at the end of this booklet.

What the standards mean for different groups

Service users, carers and the public

If you are receiving care, treatment or other services from one of our registrants, or you might do so in the future, the standards will help you to understand how our registrants should behave towards you. The standards will also be helpful if you are a carer.

On the rare occasions that something goes wrong, anyone can raise a concern through our fitness to practise process (see page 11). We can take action when there are serious concerns about a health and care professional's knowledge, skills or behaviour.

We use the standards of conduct, performance and ethics to help us decide whether we need to take action to protect the public.

Registrants and applicants

If you are registered with us, you must make sure that you are familiar with the standards and that you continue to meet them. If you are applying to be registered, you will need to sign a declaration to confirm that you will keep to the standards once you are registered.

As a registrant, you are personally responsible for the way you behave. You will need to use your judgement so that you make informed and reasonable decisions and meet the standards. You must always be prepared to justify your decisions and actions.

Making informed and reasonable decisions might include getting advice and support from colleagues, education providers, employers, professional bodies, trade unions or other people. In particular, we recognise the valuable role professional bodies play in representing and promoting the interests of their members. This often includes providing guidance and advice about good practice, which can help you meet the standards.

Students

The standards also apply to you if you are a student on an HCPC-approved programme. We have published another document, 'Guidance on conduct and ethics for students', which sets out what the standards mean for you.

The standards

1. Promote and protect the interests of service users and carers

Treat service users and carers with respect

1.1 You must treat service users and carers as individuals, respecting their privacy and dignity.

1.2 You must work in partnership with service users and carers, involving them, where appropriate, in decisions about the care, treatment or other services to be provided.

1.3 You must encourage and help service users, where appropriate, to maintain their own health and well-being, and support them so they can make informed decisions.

Make sure you have consent

1.4 You must make sure that you have consent from service users or other appropriate authority before you provide care, treatment or other services.

Challenge discrimination

1.5 You must not discriminate against service users, carers or colleagues by allowing your personal views to affect your professional relationships or the care, treatment or other services that you provide.

1.6 You must challenge colleagues if you think that they have discriminated against, or are discriminating against, service users, carers and colleagues.

Maintain appropriate boundaries

1.7 You must keep your relationships with service users and carers professional.

2 Communicate appropriately and effectively

Communicate with service users and carers

2.1 You must be polite and considerate.

2.2 You must listen to service users and carers and take account of their needs and wishes.

2.3 You must give service users and carers the information they want or need, in a way they can understand.

2.4 You must make sure that, where possible, arrangements are made to meet service users' and carers' language and communication needs.

Work with colleagues

2.5 You must work in partnership with colleagues, sharing your skills, knowledge and experience where appropriate, for the benefit of service users and carers.

2.6 You must share relevant information, where appropriate, with colleagues involved in the care, treatment or other services provided to a service user.

Social media and networking websites

2.7 You must use all forms of communication appropriately and responsibly, including social media and networking websites.

3 Work within the limits of your knowledge and skills

Keep within your scope of practice

3.1 You must keep within your scope of practice by only practising in the areas you have appropriate knowledge, skills and experience for.

3.2 You must refer a service user to another practitioner if the care, treatment or other services they need are beyond your scope of practice.

Maintain and develop your knowledge and skills

3.3 You must keep your knowledge and skills up to date and relevant to your scope of practice through continuing professional development.

3.4 You must keep up to date with and follow the law, our guidance and other requirements relevant to your practice.

3.5 You must ask for feedback and use it to improve your practice.

4 Delegate appropriately

Delegation, oversight and support

4.1 You must only delegate work to someone who has the knowledge, skills and experience needed to carry it out safely and effectively.

4.2 You must continue to provide appropriate supervision and support to those you delegate work to.

5 Respect confidentiality

Using information

5.1 You must treat information about service users as confidential.

Disclosing information

5.2 You must only disclose confidential information if:

- you have permission;
- the law allows this;
- it is in the service user's best interests; or
- it is in the public interest, such as if it is necessary to protect public safety or prevent harm to other people.

6 Manage risk

Identify and minimise risk

6.1 You must take all reasonable steps to reduce the risk of harm to service users, carers and colleagues as far as possible.

6.2 You must not do anything, or allow someone else to do anything, which could put the health or safety of a service user, carer or colleague at unacceptable risk.

Manage your health

6.3 You must make changes to how you practise, or stop practising, if your physical or mental health may affect your performance or judgement, or put others at risk for any other reason.

7 Report concerns about safety

Report concerns

7.1 You must report any concerns about the safety or well-being of service users promptly and appropriately.

7.2 You must support and encourage others to report concerns and not prevent anyone from raising concerns.

7.3 You must take appropriate action if you have concerns about the safety or well-being of children or vulnerable adults.

7.4 You must make sure that the safety and well-being of service users always comes before any professional or other loyalties.

Follow up concerns

7.5 You must follow up concerns you have reported and, if necessary, escalate them.

7.6 You must acknowledge and act on concerns raised to you, investigating, escalating or dealing with those concerns where it is appropriate for you to do so.

8 Be open when things go wrong

Openness with service users and carers

8.1 You must be open and honest when something has gone wrong with the care, treatment or other services that you provide by:

- informing service users or, where appropriate, their carers, that something has gone wrong;
- apologising;
- taking action to put matters right if possible; and
- making sure that service users or, where appropriate, their carers, receive a full and prompt explanation of what has happened and any likely effects.

Deal with concerns and complaints

8.2 You must support service users and carers who want to raise concerns about the care, treatment or other services they have received.

8.3 You must give a helpful and honest response to anyone who complains about the care, treatment or other services they have received.

9 Be honest and trustworthy

Personal and professional behaviour

9.1 You must make sure that your conduct justifies the public's trust and confidence in you and your profession.

9.2 You must be honest about your experience, qualifications and skills.

9.3 You must make sure that any promotional activities you are involved in are accurate and are not likely to mislead.

9.4 You must declare issues that might create conflicts of interest and make sure that they do not influence your judgement.

Important information about your conduct and competence

9.5 You must tell us as soon as possible if:

- you accept a caution from the police or you have been charged with, or found guilty of, a criminal offence;
- another organisation responsible for regulating a health or social-care profession has taken action or made a finding against you; or
- you have had any restriction placed on your practice, or been suspended or dismissed by an employer, because of concerns about your conduct or competence.

9.6 You must co-operate with any investigation into your conduct or competence, the conduct or competence of others, or the care, treatment or other services provided to service users.

10 Keep records of your work

Keep accurate records

10.1 You must keep full, clear, and accurate records for everyone you care for, treat, or provide other services to.

10.2 You must complete all records promptly and as soon as possible after providing care, treatment or other services.

Keep records secure

10.3 You must keep records secure by protecting them from loss, damage or inappropriate access.

Fitness to practise

When we say someone is ‘fit to practise’, we mean that they have the skills, knowledge, character and health they need to practise their profession safely and effectively.

We can consider concerns which members of the public, employers, professionals, the police and other people raise about a registrant’s fitness to practise. When we are deciding whether we need to take any action against a registrant to protect the public, we look at whether the registrant has met these standards.

You can find out more information about our fitness to practise process in our brochures ‘How to raise a concern’ and ‘What happens if a concern is raised about me’. You can download these from our website at www.hcpc-uk.org, or you can phone us on 020 7840 9806 to ask for a copy.

Glossary

Apologising

Making it clear that you are sorry about what has happened. The HCPC does not regard an apology, of itself, as an admission of liability or wrongdoing.

Carer

Anyone who looks after, or provides support to, a family member, partner or friend.

Care, treatment or other services

A general term to describe the different work that our registrants carry out.

Colleague

Other health and care professionals, students and trainees, support workers, professional carers and others involved in providing care, treatment or other services to service users.

Conduct

A health and care professional's behaviour.

Consent

Permission for a registrant to provide care, treatment or other services, given by a service user, or someone acting on their behalf, after receiving all the information they reasonably need to make that decision.

Delegate

To ask someone else to carry out a task on your behalf.

Disclose

In these standards, this refers to making a formal decision to share information about a service user with others, such as the police.

Discriminate

To unfairly treat a person or group of people differently from other people or groups of people. This includes treating others differently because of your views about their lifestyle, culture or their social or economic status, as well as the characteristics protected by law – age, disability, gender reassignment, race, marriage and civil partnership, pregnancy and maternity, religion or belief, sex and sexual orientation.

Escalate

To pass on a concern about a service user's safety or well-being to someone who is better able to act on it, for example, a more senior colleague, a manager or a regulator.

Ethics

The values that guide a person's behaviour or judgement.

Practitioner

A health and care professional who is currently practising in their profession.

Refer

To ask someone else to provide care, treatment or other services which are beyond your scope of practice or, where relevant, because the service user has asked for a second opinion.

Scope of practice

The areas in which a registrant has the knowledge, skills and experience necessary to practise safely and effectively.

Service user

Anyone who uses or is affected by the services of registrants, for example, patients or clients.

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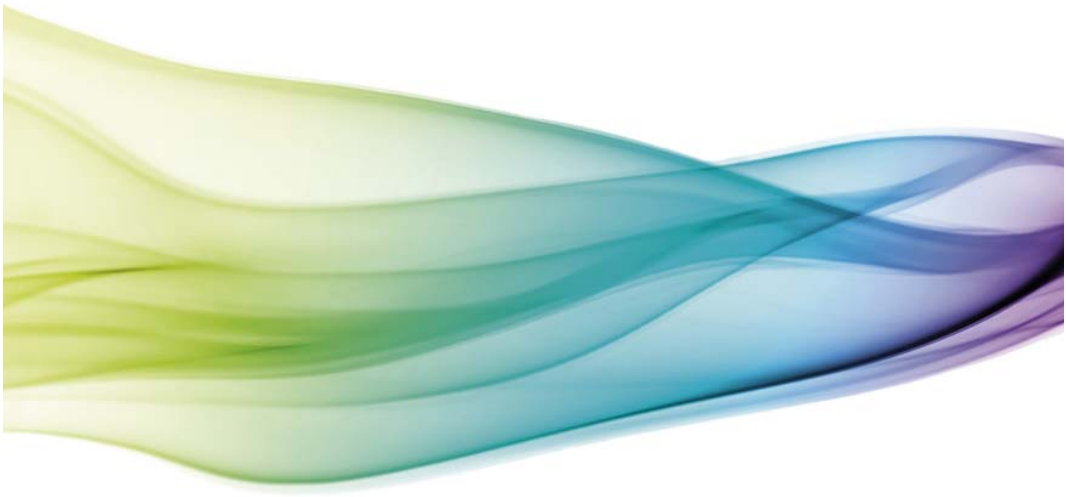
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The British Psychological Society

Code of Ethics and Conduct

Guidance published by the Ethics Committee of the British Psychological Society



August 2009

This code was written by the Ethics Committee of the British Psychological Society.

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I Introduction

a) The British Psychological Society recognises its obligation to set and uphold the highest standards of professionalism, and to promote ethical behaviour, attitudes and judgements on the part of psychologists by:

- being mindful of the need for protection of the public;
- expressing clear ethical principles, values and standards;
- promoting such standards by education and consultation;
- developing and implementing methods to help psychologists monitor their professional behaviour and attitudes;
- assisting psychologists with ethical decision making; and
- providing opportunities for discourse on these issues.

b) Under the terms of its Royal Charter, the Society is required to 'maintain a Code of Conduct'. In 1985 the Society adopted a Code of Conduct which has been regularly updated. From monitoring complaints and ethical enquiries, the Society's Ethics Committee identified a need for a code which gave more emphasis on, and support to, the process of ethical decision making.

c) This Code of Ethics and Conduct should guide all members of the British Psychological Society. It should be read in conjunction with the Society's Royal Charter, Statutes and Rules. It comes into effect in August 2009 and supersedes all previous versions. Member conduct rules came into effect on 1st July 2009. The member conduct rules provide guidance on the behaviour expected of members of the Society.

d) In formulating this code, a wide range of existing codes, as listed in the Appendix, were considered.

e) The Society has also considered the wide range of contexts in which psychologists work. The aim of the code is that it should apply to all psychologists, with the focus on the quality of decision making allowing sufficient flexibility for a variety of approaches and methods, but providing ethical standards which apply to all. Psychologists will also need to familiarise themselves with the legal framework, regulatory requirements and other guidance relevant to the particular context in which they work.

With effect from 1st July 2009, the regulator of applied psychologists will be the Health Professions Council (HPC). Members of the Society wishing to practise under one of the seven protected adjectival titles (Clinical Psychologist, Counselling Psychologist, Educational Psychologist, Forensic Psychologist, Health Psychologist, Occupational Psychologist, Sport and Exercise Psychologist) and two protected generic titles (Practitioner Psychologist and Registered Psychologist) will need to be registered with the HPC. The Society cannot determine allegations about fitness to practise. Any such allegations are referred to the Health Professions Council.

f) In this code the term 'psychologist' refers to any member of the British Psychological Society including student members. Examples of the roles undertaken by psychologists include those of colleague, consultant, counsellor, educator, employer, expert witness, evaluator, lecturer, manager, practitioner, researcher, supervisor or therapist.

g) In this code the term 'client' refers to any person or persons with whom a psychologist interacts on a professional basis. For example, a client may be an individual (such as a patient, a student, or a research participant), a couple, a family group, an educational institution, or a private or public organisation, including a court. A psychologist may have several clients at a time including, for example, those receiving, commissioning and evaluating the professional activity.

h) Psychologists are likely to need to make decisions in difficult, changing and unclear situations. The Society expects that the code will be used to form a basis for consideration of ethical questions, with the principles in this code being taken into account in the process of making decisions, together with the needs of the client and the individual circumstances of the case. However, no code can replace the need for psychologists to use their professional and ethical judgement.

i) In making decisions on what constitutes ethical practice, psychologists will need to consider the application of technical competence and the use of their professional skill and judgement. They should also be mindful of the importance of fostering and maintaining good professional relationships with clients and others as a primary element of good practice.

j) The underlying philosophical approach in this code is best described as the 'British eclectic tradition'. Moral principles and the codes which spell out their applications can only be guidelines for thinking about the decisions individuals need to make in specific cases. Variable factors are involved such as the particular circumstances, the prevailing law, the cultural context, the likely consequences and the feelings colouring the judgement. However, if moral judgments are to retain some objectivity, that is if they can be judged to be right or wrong, they must be based on rational principles which serve as criteria.

Reason by itself cannot give positive guidance but only command consistency in action which also means impartiality. Reason functions like the rules of logic, which do not tell us what to think but help our thinking to conform to rational principles. One example of a rational principle would be 'Do unto others as you would be done by'. Immanuel Kant gave expression to this in his Categorical Imperative: 'Act on such maxims as you could will to become universal law'. Our capacity to act on rational moral principles bestows on us the dignity of free moral agents and this leads to a further formulation of the Categorical Imperative: 'Treat humanity in your own person and that of others always as an end and never only as a means'. This

position forms the basis of the code.

k) This code uses the word ‘should’ rather than the more coercive ‘must’ or the permissive ‘asks’ to reinforce the advisory nature of the code as a framework in support of professional judgement. Any scrutiny of this process will consider situations in terms of the decisions made, the outcomes and the processes involved. Thinking is not optional. The code has been written primarily to guide not to punish.

l) Finally, ethics is related to the control of power. Clearly, not all clients are powerless but many are disadvantaged by lack of knowledge and certainty compared to the psychologist whose judgement they require. This code attempts to encapsulate the wisdom and experience of the Society to support its members in their professional activities, reassure the public that it is worthy of their trust and to clarify the expectations of all.

II Decision making

a) Thinking about ethics should pervade all professional activity. Ethics can be defined as the science of morals or rules of behaviour. Psychology can be defined as the scientific study of behaviour both internal (for example, cognition and feelings) and external (for example, language and actions). Thus whilst ethics and psychology are distinct, there is nevertheless an overlap as both are concerned with behaviour. Before embarking on professional work the ethical implications should be considered as part of the work context together with legal, professional and other frameworks.

b) Information from surveys of psychologists, data on queries received by the Society and information from formal complaints indicates that certain areas of work produce the majority of concerns about ethical matters.

c) These areas of concern include:

- multiple relationships – where the psychologist owes an allegiance to several different stakeholders;
- personal relationships – where the psychologist infringes or violates the trust of a client or clients;
- unclear or inadequate standards of practice – where the psychologist is unaware of or disregards the current systems in use by peers or others in similar work;
- breaches of confidentiality – where rules and constraints were broken or not clarified in advance with stakeholders;
- competence – where excessive or misleading claims are made or where inadequate safeguards and monitoring exist for new areas of work;
- research issues including falsifying data, failing to obtain consent, plagiarism or failing to acknowledge another's work or contribution.

- health problems affecting performance or conduct; and
- bringing the profession or the Society into disrepute.

d) Many of the above concerns involve unethical behaviour but others involve lack of information, poor planning or carelessness. Reflective practice, peer support and transparency of professional activity would prevent problems occurring or developing into serious concerns.

e) Despite every care being taken ethical difficulties will occur. Several systems of ethical decision making exist and the following is an adaptation of the core themes.

f) Identify the relevant issues:

- What are the parameters of the situation?
- Is there research evidence that might be relevant?
- What legal guidance exists?
- What do peers advise?
- Is there guidance available from the Health Professions Council or other relevant bodies?

g) Identify the clients and other stakeholders and consider or obtain their views.

h) Use the Code of Ethics and Conduct to identify the principles involved.

i) Evaluate the rights, responsibilities and welfare of all clients and stakeholders.

j) Generate the alternative decisions preferably with others to act as a sounding board.

k) Establish a cost/risk benefit analysis to include both short- and long-term consequences.

l) Make the decision after checking that the reasoning behind it is logical, lucid and consistent. Document the process of decision making.

m) Assume responsibility and monitor any outcomes.

n) Apologise for any negative outcomes that result. Many formal complaints are often a client's only way of obtaining an acknowledgement of distress. Saying 'sorry' does not automatically admit liability.

o) Make every effort to correct any negative outcomes and remain engaged in the process.

p) Learn from the process for yourself, for others and for the Society.

q) While the process set out in this section may appear to be a counsel of perfection, the thinking behind ethical decisions needs to be clear, especially where time is short and/or where high levels of emotion and risk are involved.

r) For further reading please see the references after the conclusion section of this code.

III Structure of the code

a) This code is based on four ethical principles, which constitute the main domains of responsibility within which ethical issues are considered. These are

- respect;
- competence;
- responsibility; and
- integrity.

b) Each ethical principle is described in a statement of values, reflecting the fundamental beliefs that guide ethical reasoning, decision making, and behaviour.

c) Each ethical principle described is further defined by a set of standards, setting out the ethical conduct that the Society expects of its members.

IV Ethical principles

1. Ethical principle: RESPECT

Statement of values – Psychologists value the dignity and worth of all persons, with sensitivity to the dynamics of perceived authority or influence over clients, and with particular regard to people's rights including those of privacy and self determination.

1.1 Standard of general respect.

Psychologists should:

(i) Respect individual, cultural and role differences, including (but not exclusively) those involving age, disability, education, ethnicity, gender, language, national origin, race, religion, sexual orientation, marital or family status and socio-economic status.

(ii) Respect the knowledge, insight, experience and expertise of clients, relevant third parties, and members of the general public.

(iii) Avoid practices that are unfair or prejudiced.

(iv) Be willing to explain the bases for their ethical decision making.

1.2 Standard of privacy and confidentiality.

Psychologists should:

(i) Keep appropriate records.

(ii) Normally obtain the consent of clients who are considered legally competent or their duly authorised representatives, for disclosure of confidential information.

(iii) Restrict the scope of disclosure to that which is consistent with professional purposes, the specifics of the initiating request or event, and (so far as required by the law) the specifics of the client's authorisation.

(iv) Record, process, and store confidential information in a fashion designed to avoid inadvertent disclosure.

(v) Ensure from the first contact that clients are aware of the limitations of maintaining confidentiality, with specific reference to:
(a) potentially conflicting or supervening legal and ethical obligations;
(b) the likelihood that consultation with colleagues may occur in order to enhance the effectiveness of service provision; and
(c) the possibility that third parties such as translators or family members may assist in ensuring that the activity concerned is not compromised by a lack of communication.

(vi) Restrict breaches of confidentiality to those exceptional circumstances under which there appears sufficient evidence to raise serious concern about:
(a) the safety of clients;
(b) the safety of other persons who may be endangered by the client's behaviour; or
(c) the health, welfare or safety of children or vulnerable adults.

(vii) Consult a professional colleague when contemplating a breach of confidentiality, unless the delay occasioned by seeking such consultation is rendered impractical by the immediacy of the need for disclosure.

(viii) Document any breach of confidentiality and the reasons compelling disclosure without consent in a contemporaneous note.

(ix) When disclosing confidential information directly to clients, safeguard the confidentiality of information relating to others, and provide adequate assistance in understanding the nature and contents of the information being disclosed.

(x) Make audio, video or photographic recordings of clients only with the explicit permission of clients who are considered legally competent, or their duly authorised representatives.

(xi) Endeavour to ensure that colleagues, staff, trainees, and supervisees with whom psychologists work understand and respect the provisions of this code concerning the handling of confidential information.

1.3 Standard of informed consent

Psychologists should:

(i) Ensure that clients, particularly children and vulnerable adults, are given ample opportunity to understand the nature, purpose, and anticipated consequences of any professional services or research participation, so that they may give informed consent to the extent that their capabilities allow.

(ii) Seek to obtain the informed consent of all clients to whom professional services or research participation are offered.

(iii) Keep adequate records of when, how and from whom consent was obtained.

(iv) Remain alert to the possibility that those people for whom professional services or research participation are contemplated may lack legal capacity for informed consent.

(v) When informed consent cannot be obtained from clients, no duly authorised representative can be identified and a pressing need for the provision of professional services is indicated, consult when feasible a person well-placed to appreciate the potential reactions of clients (such as a family member, or current or recent provider of care or services), for assistance in determining what may be in their best interests.

(vi) When the specific nature of contemplated professional services precludes obtaining informed consent from clients or their duly authorised representatives, obtain specific approval from appropriate institutional ethics authorities before proceeding. Where no institutional ethics authority exists, peers and colleagues should be consulted.

(vii) When the specific nature of research precludes obtaining informed consent from clients or their duly authorised representatives, obtain specific approval from appropriate institutional ethics authorities before proceeding. Where no institutional ethics authority exists, peers and colleagues should be consulted.

(viii) Take particular care when seeking the informed consent of detained persons, in the light of the degree to which circumstances of detention may affect the ability of such clients to consent freely.

(ix) Unless informed consent has been obtained, restrict research based upon observations of public behaviour to those situations in which persons being studied would reasonably expect to be observed by strangers, with reference to local cultural values and to the privacy of persons who, even while in a public space, may believe they are unobserved.

(x) Obtain supplemental informed consent as circumstances indicate, when professional services or research occur over an extended period of time, or when there is significant change in the nature or focus of such activities.

(xi) Withhold information from clients only in exceptional circumstances when necessary to preserve the integrity of research or the efficacy of professional services, or in the public interest and specifically consider any additional safeguards required for the preservation of client welfare.

(xii) Avoid intentional deception of clients unless:
(a) deception is necessary in exceptional circumstances to preserve the integrity of research or the efficacy of professional services;
(b) any additional safeguards required for the preservation of client welfare are specifically considered; and
(c) the nature of the deception is disclosed to clients at the earliest feasible opportunity.

1.4 Standards of self-determination

Psychologists should:

(i) Endeavour to support the self-determination of clients, while at the same time remaining alert to potential limits placed upon self-determination by personal characteristics or by externally imposed circumstances.

(ii) Ensure from the first contact that clients are aware of their right to withdraw at any time from the receipt of professional services or from research participation.

(iii) Comply with requests by clients who are withdrawing from research participation that any data by which they might be personally identified, including recordings, be destroyed.

2 Ethical Principle: COMPETENCE

Statement of values – Psychologists value the continuing development and maintenance of high standards of competence in their professional work, and the importance of preserving their ability to function optimally within the recognised limits of their knowledge, skill, training, education, and experience.

2.1 Standard of awareness of professional ethics

Psychologists should:

(i) Develop and maintain a comprehensive awareness of professional ethics, including familiarity with this Code.

(ii) Integrate ethical considerations into their professional practices as an element of continuing professional development.

2.2 Standard of ethical decision making

Psychologists should:

(i) Recognise that ethical dilemmas will inevitably arise in the course of professional practice.

(ii) Accept their responsibility to attempt to resolve such dilemmas with the appropriate combination of reflection, supervision, and consultation.

(iii) Be committed to the requirements of this Code.

(iv) Engage in a process of ethical decision making that includes:

- identifying relevant issues;
- reflecting upon established principles, values, and standards;
- seeking supervision or peer review;
- using the Code of Ethics and Conduct to identify the principles involved;

- developing alternative courses of action in the light of contextual factors;
- analysing the advantages and disadvantages of various courses of action for those likely to be affected, allowing for different perspectives and cultures;
- choosing a course of action; and
- evaluating the outcomes to inform future ethical decision making.

(v) Be able to justify their actions on ethical grounds.

(vi) Remain aware that the process of ethical decision making must be undertaken with sensitivity to any time constraints that may exist.

(vii) Given the existence of legal obligations that may occasionally appear to contradict certain provisions of this Code, analyse such contradictions with particular care, and adhere to the extent possible to these ethical principles while meeting the legal requirements of their professional roles.

2.3 Standard of recognising limits of competence

Psychologists should:

(i) Practice within the boundaries of their competence.

(ii) Engage in Continued Professional Development.

(iii) Remain abreast of scientific, ethical, and legal innovations germane to their professional activities, with further sensitivity to ongoing developments in the broader social, political and organisational contexts in which they work.

(iv) Seek consultation and supervision when indicated, particularly as circumstances begin to challenge their scientific or professional expertise.

(v) Engage in additional areas of professional activity only after obtaining the knowledge, skill, training, education, and experience necessary for competent functioning.

(vi) Remain aware of and acknowledge the limits of their methods, as well as the limits of the conclusions that may be derived from such methods under different circumstances and for different purposes.

(vii) Strive to ensure that those working under their direct supervision also comply with each of the requirements of this standard and that they are not required to work beyond the limits of their competence.

2.4 Standard of recognising impairment

Psychologists should:

(i) Monitor their own personal and professional lifestyle in order to remain alert to signs of impairment.

(ii) Seek professional consultation or assistance when they become aware of health-related or other personal problems that may impair their own professional competence.

(iii) Refrain from practice when their professional competence is seriously impaired.

(iv) Encourage colleagues whose health-related or other personal problems may reflect impairment to seek professional consultation or assistance, and consider informing other potential sources of intervention, including, for example, the Health Professions Council, when such colleagues appear unable to recognise that a problem exists. Psychologists must inform potential sources of intervention where necessary for the protection of the public.

3 Ethical Principle: RESPONSIBILITY

Statement of Values – Psychologists value their responsibilities to clients, to the general public, and to the profession and science of Psychology, including the avoidance of harm and the prevention of misuse or abuse of their contributions to society.

3.1 Standards of general responsibilty

Psychologists should:

(i) Avoid harming clients, but take into account that the interests of different clients may conflict. The psychologist will need to weigh these interests and the potential harm caused by alternative courses of action or inaction.

(ii) Avoid personal and professional misconduct that might bring the Society or the reputation of the profession into disrepute, recognising that, in particular, convictions for criminal offences that reflect on suitability for practice may be regarded as misconduct by the Society.

(iii) Seek to remain aware of the scientific and professional activities of others with whom they work, with particular attention to the ethical behaviour of employees, assistants, supervisees and students.

(iv) Psychologists have a responsibility to be mindful of any potential risks to themselves.

3.2 Standards of termination and continuity of care

Psychologists should:

(i) Make clear at the first contact, or at the earliest opportunity, the conditions under which the professional services may be terminated.

(ii) Take advice where there appears to be ambiguity about continuing with professional services.

(iii) Terminate professional services when clients do not appear to be deriving benefit and are unlikely to do so.

(iv) Refer clients to alternative sources of assistance as appropriate, facilitating the transfer and continuity of care through reasonable collaboration with other professionals.

3.3 Standard of protection of research participants

Psychologists should:

(i) Consider all research from the standpoint of research participants, for the purpose of eliminating potential risks to psychological well-being, physical health, personal values, or dignity.

(ii) Undertake such consideration with due concern for the potential effects of, for example, age, disability, education, ethnicity, gender, language, national origin, race, religion, marital or family status, or sexual orientation, seeking consultation as needed from those knowledgeable about such effects.

(iii) Ask research participants from the first contact about individual factors that might reasonably lead to risk of harm, and inform research participants of any action they should take to minimise such risks.

(iv) Refrain from using financial compensation or other inducements for research participants to risk harm beyond that which they face in their normal lifestyles.

(v) Obtain the considered and non-subjective approval of independent advisors whenever concluding that harm, unusual discomfort, or other negative consequences may follow from research, and obtain supplemental informed consent from research participants specific to such issues.

(vi) Inform research participants from the first contact that their right to withdraw at any time is not affected by the receipt or offer of any financial compensation or other inducements for participation.

(vii) Inform research participants from the first contact that they may decline to answer any questions put to them, while conveying as well that this may lead to termination of their participation, particularly when safety issues are implicated.

(viii) Inform research participants when evidence is obtained of a psychological or physical problem of which they are apparently unaware, if it appears that failure to do so may endanger their present or future well-being.

(ix) Exercise particular caution when responding to requests for advice from research participants concerning psychological or other issues, and offer to make a referral for assistance if the inquiry appears to involve issues sufficiently serious to warrant professional services.

(x) When conducting research involving animals,
(a) observe the highest standards of animal welfare, including reduction to the minimum of any pain, suffering, fear, distress, frustration, boredom, or lasting harm; and
(b) avoid the infliction of any of these conditions which cannot be strictly justified, in adherence to the Society's published *Guidelines for Psychologists Working with Animals*.

3.4 Standard of debriefing of research participants

Psychologists should:

(i) Debrief research participants at the conclusion of their participation, in order to inform them of the outcomes and nature of the research, to identify any unforeseen harm, discomfort, or misconceptions, and in order to arrange for assistance as needed.

(ii) Take particular care when discussing outcomes with research participants, as seemingly evaluative statements may carry unintended weight.

4 Ethical principle: INTEGRITY

Statement of values – Psychologists value honesty, accuracy, clarity, and fairness in their interactions with all persons, and seek to promote integrity in all facets of their scientific and professional endeavours.

4.1 Standard of honesty and accuracy

Psychologists should:

(i) Be honest and accurate in representing their professional affiliations and qualifications, including such matters as knowledge, skill, training, education, and experience.

(ii) Take reasonable steps to ensure that their qualifications and competences are not misrepresented by others, and to correct any misrepresentations identified.

(iii) Be honest and accurate in conveying professional conclusions, opinions, and research findings, and in acknowledging the potential limitations.

(iv) Be honest and accurate in representing the financial and other parameters and obligations of supervisory, training, employment, and other contractual relationships.

(v) Ensure that clients are aware from the first contact of costs and methods of payment for the provision of professional services.

(vi) Claim only appropriate ownership or credit for their research, published writings, or other scientific and professional contributions, and provide due acknowledgement of the contributions of others to a collaborative work.

(vii) Be honest and accurate in advertising their professional services and products, in order to avoid encouraging unrealistic expectations or otherwise misleading the public.

4.2 Standard of avoiding exploitation and conflicts of interest

Psychologists should:

(i) Remain aware of the problems that may result from dual or multiple relationships, for example, supervising trainees to whom they are married, teaching students with whom they already have a familial relationship, or providing psychological therapy to a friend.

(ii) Avoid forming relationships that may impair professional objectivity or otherwise lead to exploitation of or conflicts of interest with a client.

(iii) Clarify for clients and other relevant parties the professional roles currently assumed and conflicts of interest that might potentially arise.

(iv) Refrain from abusing professional relationships in order to advance their sexual, personal, financial, or other interests.

(v) Recognise that conflicts of interests and inequity of power may still reside after professional relationships are formally terminated, such that professional responsibilities may still apply.

4.3 Standard of Maintaining Personal Boundaries

Psychologists should:

(i) Refrain from engaging in any form of sexual or romantic relationship with persons to whom they are providing professional services, or to whom they owe a continuing duty of care, or with whom they have a relationship of trust. This might include a former patient, a student or trainee, or a junior staff member.

(ii) Refrain from engaging in harassment and strive to maintain their workplaces free from sexual harassment.

(iii) Recognise as harassment any unwelcome verbal or physical behaviour, including sexual advances, when
(a) such conduct interferes with another person's work or creates an intimidating, hostile or offensive working environment;
(b) submission to this conduct is made implicitly or explicitly a term or condition of a person's education, employment or access to resources; or
(c) submission or rejection of such conduct is used as a basis for decisions affecting a person's education or employment prospects.

(iv) Recognise that harassment may consist of a single serious act or multiple persistent or pervasive acts, and that it further includes behaviour that ridicules, disparages, or abuses a person.

(v) Make clear to students, supervisees, trainees and employees, as part of their induction, that agreed procedures addressing harassment exist within both the workplace and the Society.

(vi) Cultivate an awareness of power structures and tensions within groups or teams.

4.4 Standard of Addressing Ethical Misconduct

Psychologists should:

(i) Challenge colleagues who appear to have engaged in ethical misconduct, and/or consider bringing allegations of such misconduct to the attention of those charged with the responsibility to investigate them, particularly when members of the public appear to have been, or may be, affected by the behaviour in question.

(ii) When bringing allegations of misconduct by a colleague, do so without malice and with no breaches of confidentiality other than those necessary to the proper investigatory processes.

(iii) When the subject of allegations of misconduct themselves, take all reasonable steps to assist those charged with the responsibility to investigate them.

IV CONCLUSION

This Code provides the parameters within which professional judgements should be made. However, it cannot, and does not aim to, provide the answer to every ethical dilemma a psychologist may face. It is important to remember to reflect and apply a process to resolve ethical dilemmas as set out in this code.

If you have a question about the code or about professional ethics, there are several potential sources of advice. There is a dedicated Code of Ethics and Conduct area on the Society's website (www.bps.org.uk). Ethical advice and support for members can be obtained by e-mailing either **practice-ethics@bps.org.uk** or **research-ethics@bps.org.uk**.

The Society cannot give legal advice, or provide practical support to members who have been complained about. For that reason, the Society strongly recommends that members consider taking out professional indemnity insurance. The Society has approved an insurance scheme, and details are available from the Society, but there are other insurance policies that members could consider.

The Society cannot determine allegations about fitness to practise. Any such allegations are referred to the Health Professions Council (http://www.hpc-uk.org/; email: **ftp@hpc-uk.org**; telephone: 0800 328 4218; or write to: Health Professions Council, Park House, 184 Kennington Park Road, London SE11 4BU).

All allegations against Society members will be dealt with in accordance with the Member Conduct Rules.

This code was written by the Ethics Committee of the British Psychological Society. Thanks are due to all the current and former members of the Committee and all those who assisted in the drafting of earlier versions the code, with particular thanks to representatives of Witness (formerly POPAN: the Prevention of Professional Abuse Network), the philosophers Baroness Mary Warnock and Professor Peter Rickman and last but not least to Dr Eric Drogin and Professor John Williams.

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APPENDIX

Main documents consulted in preparing the Code of Ethics and Conduct.

United Nations Universal Declaration of Human Rights (1948)

World Medical Association Declaration of Helsinki (1964, last amended 2000)

European Convention on Human Rights and Fundamental Freedoms (1963, last amended 1985)

Meta-Code of Ethics and Carte Ethica – European Federation of Psychologists Associations (1995)

Code of Professional Ethics – The Psychological Society of Ireland (1999)

Canadian Code of Ethics for Psychologists – Canadian Psychological Association (2000)

Ethical Principles of Psychologists and Code of Conduct – American Psychological Association (2002)

Ethical Framework for Good Practice in Counselling and Psychotherapy – British Association for Counselling and Psychotherapy (2002)

Ethical Requirements for Member Organisations – United Kingdom Council for Psychotherapy (2003)

Standards in Applied Psychology – National Occupational Standards Board

Confidentiality – General Medical Council (2004)

Whistleblowers Policy Pack – Public Concern at Work (2003)

The Local Authorities (Model Code of Conduct) (England) Order (2001)

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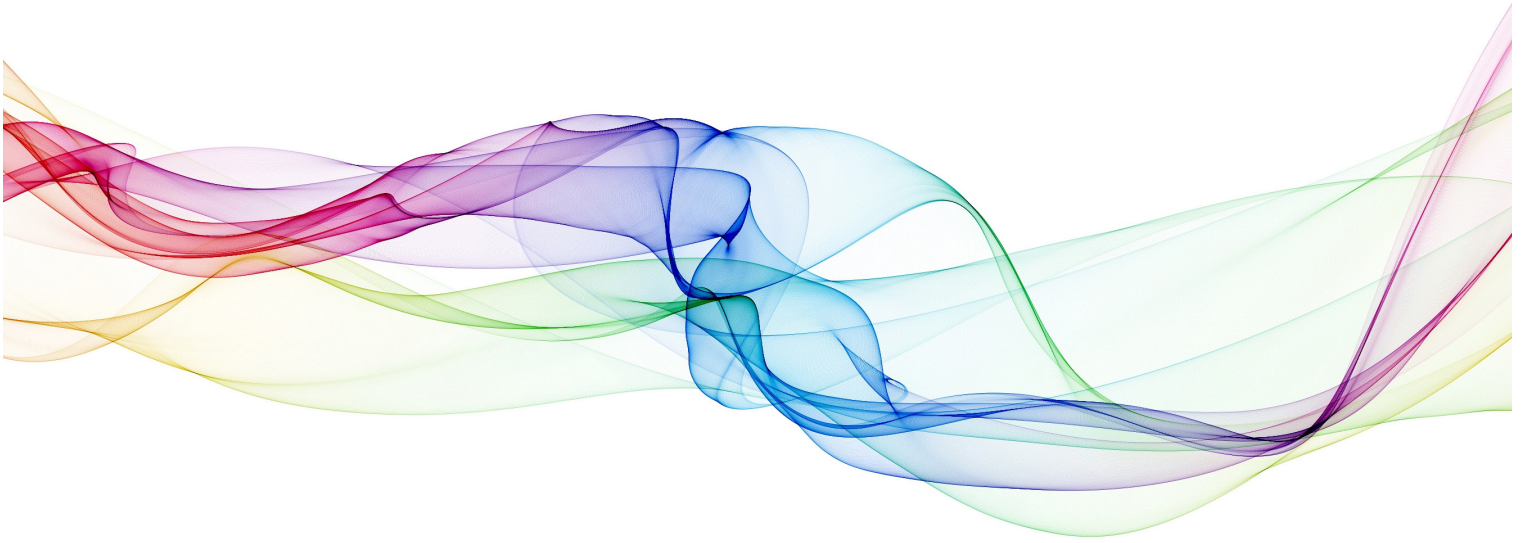
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The British Psychological Society
Promoting excellence in psychology

Practice Guidelines

Third edition



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Preface

This Third Edition of the Practice Guidelines replaces the second edition published in 2009. Legislation, practice and technology have moved on since then and these changes are captured in the new guidance.

This edition of the guidelines was produced through the British Psychological Society's Professional Practice Board by a working group drawn from the range of Member Networks across The Society whose members are engaged in professional practice, as well as representatives from relevant expert reference groups of The Society, in particular areas of practice. Further information is available in ***Appendix 3: How this document has been developed.***

These Practice Guidelines aim to define good practice for all psychologists whether registered, chartered or in training and offer guidance for decision making. The Guidelines have been designed for broad application across the full range of applied psychology.

The first part of the guidance (sections 1–3) set out considerations for psychologists on different contexts of practice. The second part of the guidance (sections 4–8) sets out guidance for psychologists on how to manage work with clients.

It is recognised that in addition psychologists may require more detailed guidance for some particular roles and responsibilities or for particular situations in which they work. Further information is available in the ***Appendices***.

The Society expects that the guidelines will be used to form a basis for consideration, with the principles being taken into account in the process of decision-making, together with the needs of others and the specific circumstances. No guidance can replace the need for psychologists to use their own professional judgement. Effective practice means exercising this professional judgement in a defensible way that does not put clients or the public at risk, or undermine, or call into question the reputation of the profession as a whole.

The Guidelines will be reviewed in accordance with Society policy within a maximum period of five years in order to reflect current legislation, evidence and practice contexts. Psychologists using the Practice Guidelines should do so in conjunction with the ***BPS Code of Ethics and Conduct*** and the ***BPS Code of Human Research Ethics***, as necessary.



Glossary of terms

Client

The Society's *Code of Ethics and Conduct* uses the term person or people throughout, this is in recognition of the fact that the document is generic and may be used by all psychologists; academics, researchers, students and practitioners alike.

Throughout this Practice Guidelines document the term 'client' is used and refers to any person or persons with whom a psychologist interacts on a professional basis.

For example, the 'client' may be a couple, a family group, an educational institution, a community organisation or group or a private or public organisation including a court, an individual (sometimes referred to as, for example, athlete, child/young person, patient, prisoner, coachee, service user, stakeholder, leader, or student), who are in receipt of the services of the psychologist.

Psychologist

Throughout this Practice Guidelines document the term 'psychologist' is used and refers to all psychologists whether registered, chartered or in training who provide psychological services across the full range of applied psychology, in any context of practice.

1. How psychologists work

1.1 Legal and professional obligations of psychologists

Psychologists' professional practice is impacted upon and governed by a range of legislation and regulation. Particular psychological disciplines may also need to consider additional legislation, regulation and guidelines. It is the psychologist's responsibility to ensure they are aware of the legislation and guidelines that govern their particular area of practice as well as the terms of their employment or terms contracted with a commissioner of their services.

Psychologists are also advised to consider membership of a union or similar body to ensure they have access to appropriate representation, support and legal advice should they be subject to a complaint or disciplinary action, or require support for example with an employment grievance, which may be related to concerns over quality and standards of psychological service provision.

Further information is available in the ***Appendices***. Important examples to note are:

Health and Care Professions Council (HCPC) Registration

It is a statutory requirement for all psychologists wishing to practice using one of the titles protected by the HCPC to register with the HCPC. Unregistered psychologists offering services to the public in any of the domains regulated by the HCPC may commit an offence by doing so, even if they refrain from using protected titles, provided intent to deceive can be proved. The Society's position is that it is in the interests of both the public and the profession for all psychologists providing services in a regulated domain to be registered with the HCPC.

Professional competence

Psychologists should value the continuing development and maintenance of high standards of competence in their practice and the importance of working within the recognised limits of their knowledge, skill, training, education, and experience. Psychologists should consider advances in the evidence base, the need to maintain technical and practical skills and knowledge and the limits of their competence. This is stipulated in both the ***BPS Code of Ethics and Conduct*** and the ***HCPC Standards of Proficiency***.

Professional indemnity insurance

The UK Government has introduced legislation (The Health Care and Associated Professions (Indemnity Arrangements) Order 2014) which now makes it mandatory for health professionals to have a professional indemnity arrangement in place. The HCPC has made having such an arrangement in place a condition of registration.

This may be achieved either through the employer or through a privately arranged policy. An employer's insurance may provide cover only for a negligence claim but not for the costs of a disciplinary hearing. It is the psychologist's responsibility to check carefully that

they have cover in place that meets their personal/professional needs. Further information is available in the ***Society document: Career Support and Development.***

Disclosure and Barring Service (DBS) Checks

Psychologists working in certain fields, for example with children or in healthcare, will need to demonstrate they have had a satisfactory criminal records check at the appropriate level for the nature of the work undertaken.

Applicants will be provided with a certificate to demonstrate this. Applicants cannot request a check personally, this can be requested by a psychologist's employer. For psychologists practising independently the Society offers this as a service to members. Further information is available on the ***Society Website: https://beta.bps.org.uk/Practice-Guidelines***

Equality Act 2010

This Act protects people against unfair treatment, promotes equality and prevents discrimination against any of nine protected characteristics: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex, and sexual orientation. Respect is a core ethical value for psychologists and a commitment to equality of opportunity is embedded in all aspects of psychological practice. Psychologists, where they operate in an organisational context, must also seek to encourage and influence others in ensuring that equality of opportunity is embedded in all thinking and all practice relating to access to services for client groups and recruitment and employment practices.

Providers of service to the public must also make reasonable adjustments for people who have a disability under the Act. This requirement is anticipatory so requires consideration, and adjustment where reasonable, of any barriers which may prevent a person with a disability from using a service.

Data Protection Act 1998

The Data Protection Act defines personal and sensitive personal data, and data must be processed in accordance with eight principles. It gives individuals the right to know what information is held about them and provides a framework to ensure that personal information is handled properly.

Good information governance is at the heart of safe practice. It encompasses physical data security, access controls and acceptable use, data quality, and records management, among other things. Psychologists must have appropriate security to prevent any personal data held from being accidentally or deliberately compromised. In most circumstances, independent practitioners will also need to register as a data controller with the Information Commissioner's Office.

Further information is available in ***Section 7.1: Information governance, Appendix 1: Relevant legislation*** and ***Society Document: Data Protection Act 1998 – Guidelines for Psychologists.***

Freedom of Information Act 2000

The Freedom of Information Act 2000 provides public access to information held by public authorities. Public authorities include government departments, local authorities, the NHS, State schools and police forces.

It does this in two ways:

- public authorities are obliged to publish certain information about their activities; and
- members of the public are entitled to request information from public authorities.

The Act covers any recorded information that is held by a public authority in England, Wales and Northern Ireland, and by UK-wide public authorities based in Scotland. Information held by Scottish public authorities is covered by Scotland's own Freedom of Information (Scotland) Act 2002.

This legislation permits information to be withheld from disclosure in certain prescribed circumstances, for example information provided in confidence, related to law enforcement or where it relates to personal matters.

Health and Safety at Work Act 1974

This Act places a duty on all employers 'to ensure, so far as is reasonably practicable, the health, safety and welfare at work' (Part 1, Section 2.1) of all their employees. Employees themselves also have obligations under the legislation.

Working together to safeguard children guidance

The Government website provides statutory guidance on inter-agency working to safeguard and promote the welfare of children. Statutory guidance is issued by law; it must be followed unless there is a good reason not to. All organisations, including charities, are expected to comply with this government inter-agency statutory guidance. Psychologists have a duty of care to both their clients and the public. Any allegations of abuse, either ongoing or historic, must be taken seriously and consideration must be given about breaking confidentiality especially in cases where other vulnerable people may be at risk. Further information is available in ***Section 4: Safeguarding***.

Mental Capacity Act 2005

The Mental Capacity Act (2005) provides a clear and comprehensive framework with regard to capacity and consent for all individuals aged 16 years and above in England and Wales.

There are five key principles set out in the Act which underpin practice (quoted from legislative source):

(i) A person must be assumed to have capacity unless it is established that he lacks capacity.

(ii) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

(iii) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

(iv) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
(v) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

In Scotland the Adults with Incapacity (Scotland) Act 2000 applies and in Northern Ireland the Mental Capacity Act (Northern Ireland) 2016 is used.

Mental Health Act 1983 as amended 2007

The main purpose of the Mental Health Act 1983 as amended 2007 (MHA) is to allow compulsory action to be taken, where necessary, to ensure that people with mental disorders receive the care and treatment they require for their own health or safety, or for the protection of other people.

The Act sets out the criteria that must be met before compulsory measures can be taken, along with protections and safeguards for patients. The Code of Practice[1] provides statutory guidance for mental health professionals on how they should carry out their responsibilities in practice under the MHA. Although the Act allows for people to be compulsorily detained and treated without their consent if required, empowerment and involvement of patients as far as is possible is required by the Code of Practice.

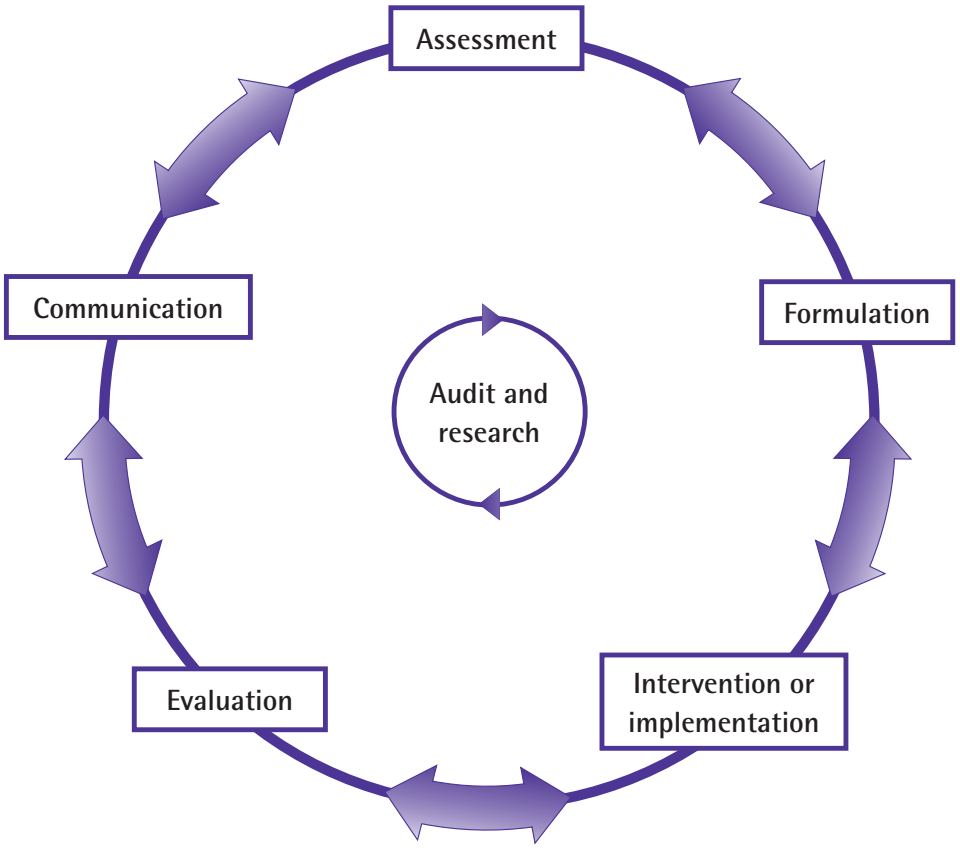
Those involved in working with people subject to provisions of the MHA, including psychologists, must understand and give consideration to the five key principles set out in the Code:
(i) least restrictive option and maximising independence;
(ii) empowerment and involvement;
(iii) respect and dignity;
(iv) purpose and effectiveness; and
(v) efficiency and equity.

1.2 Cycle of professional practice

The professional practice of psychologists is underpinned by four key ethical values – Respect, Competence, Responsibility and Integrity – and five core skills:

- **assessment** and establishment of agreements with the client;
- **formulation** of client needs and problems;
- **intervention or implementation** of solutions;
- **evaluation** of outcomes; and
- **communication** through reporting and reflecting on outcomes.

These core competencies flow and inform each other as illustrated below.



Assessment and establishment of agreements with the client

Assessment of psychological processes and behaviour is derived from the theory and practice of both academic and applied psychology. It includes both assessing change and stability, and comparison with others. Assessment procedures used will depend heavily on the practice context and may include:

- the development and use of psychometric tests following best practice;
- the application of systematic observation and measurement of behaviour in a range of contexts and settings;
- devising structured assessment strategies for individual clients, teams and organisations; and
- the use of a range of interview processes with clients, carers, other stakeholders and other professionals.

Results of these assessments are integrated within the context of the historical, dynamic and developmental processes that will have shaped the client as well as future aspirations or needs. Psychologists have the ability to assess the suitability of different measurement procedures, depending on the purpose for which the assessment is needed, as well as being competent to devise and use context-specific procedures.

Formulation of client needs and problems

Formulation is the summation and integration of the knowledge that is acquired by the assessment process. This will draw on psychological theory and research to provide a framework for describing a client's needs. Because of their particular training in the relationship of theory to practice, psychologists will be able to draw on a number of models to meet needs or support decision-making. This process provides the foundation from which actions derive. What makes this activity unique to psychologists is the knowledge base, experience and information on which they draw. The ability to access, review, critically evaluate, analyse and synthesise data and knowledge from a psychological perspective is one that is distinct to psychologists, both academic and applied.

Intervention or implementation of solutions

This will be the stage where the client's needs, as described by formulation, begin to be met. This may involve the use of psychological models or approaches to, for example, facilitate change, solve a problem or improve the quality of a relationship. All these interventions, or implementation of solutions, are tests of the provisional hypotheses contained in the formulation, and are subject to repeated modification in the light of experience and new data.

Evaluation of and reflecting on outcomes

Evaluation is used to measure the effectiveness of activities and interventions both during and after their implementation. The results of any evaluation and reflection will impact the next steps taken by a psychologist.

Although employers and others may demand certainty about outcomes, psychologists should always be careful to make it clear that they are able to provide only interpretations of behaviour, and advice and guidance, rather than necessarily predicting future behaviours.

Communication through reporting

Communication skills are integral to all aspects of a psychologist's role. Effective communication skills are essential in relation to all aspects of work with others. Communication skills include communication with clients, all forms of electronic and verbal communication, professional letters and reports, and the dissemination of research findings.

Audit and research

Audit and research underpin the cycle, as they help to inform all stages of professional practice.

Audit aims to evaluate how close assessment, formulation, intervention and implementation are against a set of previously given standards of practice. Audit also evaluates how protocols and procedures, for example related to consent or recording of activity, have been followed.

Research provides the evidence base for the practice of psychology. Research methods in psychology vary from qualitative observation to quantitative scientific method, so it is important to distinguish the nature and quality of the evidence underpinning any knowledge or techniques being applied. In general, basic research develops theories, models and data to describe and explain psychological processes and structures, while primary research develops and evaluates ways of using psychological knowledge to intervene with people, organisations, processes or technologies to achieve desired effects. Secondary research consolidates other research to identify higher order trends and directions.

1.3 Reflective practice

One of the key processes that should be encouraged for psychologists is having a complex understanding of self in the context of others. The HCPC requires reflection in the record of continued professional development in order to retain continued registration.

Psychologists will need to make decisions about clients which may have a profound impact on their lives. Decision-making is often subject to various competing biases. Psychologists should be aware of the possibility that they may be influenced by considerations which are not driven by professional knowledge, skills or experience. Maintaining awareness of these biases is important when trying to think through dilemmas.

Sources of influence and bias may include:

- **Cognitive Biases –** Over 150 have been described[2,3,4] including salience (how readily something comes to mind), confirmation bias (the human tendency to look for evidence that confirms their belief and to ignore other evidence), loss aversion (risky behaviour to avoid loss), beliefs about disclosure (tendency to be more honest when they believe their actions will be known by others), and dissonance reduction (justifying actions if consequences are considered worth it).
- **Personal Experience –** the experience of the psychologist may affect how they view or treat a client or situation. This may include current or historical trauma, or the kind of organisation and culture with which they are most familiar. Interventions which may be appropriate in one context may be ineffective and cause distress in another.
- **Motivation –** the original reasons for undertaking the profession may change or be challenged due to fatigue or experience within the profession which may affect the psychologist's viewpoint.
- **Health –** psychologists should be mindful of the potential effect of health conditions or medications which they may be taking, on their practice.
- **Control over the psychologist's own practice –** this refers to clarity and openness in the management of the psychologist's business and maintaining the professional's autonomy in their interactions with clients.
- **Pro bono public work –** psychologists are encouraged, and personally motivated to

engage with such work, while being mindful of impact on the value that is placed on the profession as a whole.
- **An unethical environment –** maintaining self-recognition of what the appropriate ethical standard should be, irrespective of the prevailing situation.
- **Environment –** political realities may lead the psychologist to make compromises; while there is nothing wrong with compromises, their constant use may mean a decline in overall standards.

The literature is generally pessimistic about the ability of practitioners to overcome some of these biases, considering them to be inherent in human thinking patterns. By being aware of and acknowledging them, it can be possible to manage their influence. For example, biases can be levelled out by presenting information in different ways, by engaging the perspectives of people with different experiences and expectations, or by priming thinking with different examples.

A key factor in developing and maintaining these skills is the use of consultation or supervision and having a space where it is possible to open up thinking to the mind of another with a view to extending knowledge about the self.

It is important that psychologists from all disciplines look after their own wellbeing. This is not only important for them as individuals, but also for the quality of the care they give their clients. In their practice and, for example, within their CPD plans and supervision psychologists should consider self-care and how they can maintain their own wellbeing.

It is also important for psychologists to evaluate effectiveness of practice, by welcoming feedback from clients. This can be difficult due to fears of criticism but reflective practitioners are eager to improve and welcome any feedback that will support this process.

1.4 Continuing professional development

Continuing professional development (CPD) is the professional and work-related aspect of lifelong learning. It is an integral part of the process of adapting to change, and essential for maintaining and enhancing professionalism and competence. The Society provides an online facility to record CPD, further information is available on the ***Society website: http://beta.bps.org.uk/Practice-Guidelines.***

- CPD is both a professional expectation and an individual responsibility to taking a structured and self-managed approach to further learning through:
  - actively engaging in a range of CPD
  - maintaining a record of CPD
  - applying learning from CPD to professional practice.
- There is a range of formal and informal learning activities that may be used for CPD and it is recommended that psychologists engage in a mix of CPD activities.
- Professional development is not purely about inputs (i.e. undertaking CPD activities); it also requires a reflective, outcomes-based approach which focuses on the learning gained from CPD and its application to current or future practice, together with the associated benefits for clients and the services provided.

- All members who are registered with the HCPC are required to comply with their CPD requirements as a condition of continued professional registration. Further information is available in ***Appendix 2: Websites and further information***

Mentoring

Psychologists may seek a mentoring relationship with colleagues in order to focus their attention on skills to add to their competencies. Psychologists taking on the role of mentor often support the psychologist with their career path. Early career psychologists may find it beneficial to be mentored by a more experienced psychologist.

1.5 Consultation/supervision

Consultation or supervision is considered an essential part of good practice as a psychologist. There is no legal requirement for supervision, although it is considered an ethical and professional expectation to engage in appropriate consultation in order to support effective practice. Provision of this is therefore an important underpinning to good quality service delivery. The Society's position is, for safe and effective practice in clinical and mental health settings, or with other vulnerable groups, supervision is a requirement of practice.

The objectives of consultation/supervision are:

- to provide practitioners with consultation on their work with clients;
- to enhance the quality and competence of practice offered to all clients;
- to offer psychologists intellectual challenge enabling reflection, transformational learning and psychological support to maximise their responsibility for appropriate self-care; and
- to contribute to the CPD of both psychologist and supervisor by developing competence in the use and practise of supervision.

All aspects of practice are appropriate for discussion in supervision, including research activity, administrative and managerial work, service developments, team working, teaching and the process of supervising others. Supervision is not personal therapy and nor is it a form of, or substitute for, line management or appropriate training.

For psychologists working in a wide range of settings such as therapeutic and organisational settings, supervision is a core component of the psychologist's CPD. For some areas of practice, the nature of supervision changes over time. This may be unique to each psychologist and the context of their application. Expectations should be agreed from the outset and reviewed at appropriate intervals.

Forms of consultation/supervision

Supervision may take the form of clinical supervision, mentoring, coaching, supervision on placement/work setting, tutorials and peer support. Psychologists may engage in one to one supervision; group supervision (facilitated or non-facilitated) or peer supervision and any of these may be face to face or virtual. Whilst it should not be a substitute for line management, a psychologist's supervisor may also be their line manager.

Those working in independent practice, or in the absence of service-based supervision, should seek supervision from appropriately qualified and experienced personnel as appropriate. Peer supervision (individual or group) may be an appropriate way to find collegial support.

Psychologists may select different supervisors, depending on their preferred supervisory style, nature, orientation and their needs at the time. Particularly for experienced psychologists, this may be from an experienced colleague from outside their profession, professional specialty or organisation. Psychologists could also invite supervision from experts by experience for whom they provide services, where appropriate to the context of practice.

The Society maintains the Register of Applied Psychology Practice Supervisors (RAPPS), which recognises psychologists with special expertise in supervision and supervisory practice. Further information is available on the ***Society Website: http://beta.bps.org.uk/Practice-Guidelines***.

Amount of supervision

While there is a specified number of supervision sessions for trainees (e.g. for their Chartered status) which varies across different sub-disciplines of psychology, no definitive amount of supervision is specified as part of CPD. To determine both the quantity and nature of the supervision, the psychologist may consider their need for supervision from various perspectives: their own assessment of need, the competencies required for their practice; the context of their work; organisational requirements; and the support available. For psychologists in employment the arrangements for consultation/supervision should be agreed after considering these factors in consultation with the employer.

Roles and responsibilities of the supervisor

Psychologists undertaking supervision should ensure that they are sufficiently experienced, competent and appropriately trained to provide supervision. Psychologists are often called upon to supervise non-psychologists, in which case these guidelines would also apply.

In supervision, the psychologist as supervisor needs be aware of their own competence in relation to the work of the psychologist and, where necessary, recommend additional supervisors who may have the appropriate level of expertise. Psychologists may offer consultancy supervision to professional colleagues, organisations and stakeholders in line with their competencies.

Psychologists should avoid personal relationships between the supervisor and psychologist which could adversely affect integrity and objectivity.

Psychologists providing consultation/supervision should do so in line with the guidance in other relevant sections of these Practice Guidelines.

Issues of power and control

The nature of supervision itself creates a power imbalance, even between peers. Both the person providing supervision and the person receiving it need to be aware of this.

The supervisory leadership relationship should be both informative and reflective. Psychologists in leadership roles as supervisors should provide regular, informative feedback to the psychologist as well as motivating them to reflect on their own practice, continue to self-assess and improve self-awareness.

1.6 Leadership

Psychologists at any stage of their career are likely to find themselves in a position where they are required to demonstrate or model leadership. This may be an integral part of their practitioner work or may arise through being a leader of a team, including leading in Society work. Leadership is widely quoted and described in the context of leading change as, *'accepting responsibility to create conditions that enable others to achieve shared purpose in the face of uncertainty'*[5]. Furthermore, leaders 'can create conditions interpersonally, structurally, and/or procedurally'[6]. These descriptors highlight the often complex process of psychological change through clinical intervention and also through leading others.

Contemporary leadership styles are generally more aligned to working *within* a team or a system rather than being directive. Leading as a psychologist is likely to include dealing with highly complex information and systems whatever the context. Leading in this way demands high levels of skill in developing, managing and maintaining professional relationships. This may include communicating complex and sensitive information, and reflexivity to enable individuals and teams to co-formulate around difficulty and challenge.

2. Where psychologists work

2.1 Working environment

When undertaking work with clients, psychologists need to give consideration to providing an environment which is welcoming, accessible, safe, and offers privacy. Although choice of workspace is not always available, it is important wherever work takes place with clients that psychologists consider:

- whether lighting, acoustics, heating and seating are comfortable;
- whether confidential conversations may be audible to others;
- whether there are arrangements to ensure client and practitioner safety, for example through easy access to another member of staff if a difficulty arises;
- whether access and exits are safe, well-lit and in areas which are likely to be overseen;
- that reasonable adjustments can be made to support effects of special needs and/or disability;
- whether the setting is culturally acceptable to clients; and
- whether there are facilities and equipment suitable for the clients, for example lavatories, play materials for children.

Where context of practice allows, psychologists could seek the assistance of relevant workplace representatives, for example their trade union representative or human resources staff, in situations where appropriate workplace conditions are not being provided. However, it is acknowledged that sometimes the ideal workspace may not be available or that psychologists may not have access to these workplace representatives due to their context of practice and psychologists should, within the limits of safe practice, be able to adapt to situations within local constraints in order to provide the best service for clients.

Sometimes, it is important to work with clients in representative environments in order to understand behavioural drivers. This will apply if the psychologist's task is to understand behaviours in such environments and provide support, for example through the use of technology, design of procedures, training or team design. Psychologists should consider carefully how to create representative conditions without causing harm. Equally it may sometimes be necessary for psychologists to work in a client's own context as that is where any intervention may be formulated or put in place. Psychologists should ensure they follow the relevant health and safety guidelines in place at their working location even if that location is not their usual place of work.

There may be a temptation to make assumptions about what sort of environment is most suitable, comfortable and culturally appropriate for clients, however it is helpful to ask them and endeavour to make appropriate adjustments to meet their needs.

Lone working

Many psychologists practise in a lone worker workplace and on occasion visit clients in their own homes. When working at home, it is necessary to ensure the proper insurance

and protocols for this type of work, as well as manage boundaries between personal and private space. When working alone, the Suzy Lamplugh Trust recommends always ensuring that someone else has access to schedules and contact details for clients. Psychologists may also want to put in place a 'code word call', where should they fail to answer or speak the correct code word, the police are alerted. This is just an example of an additional safety practice, and there may be different ideas for ensuring personal safety when lone working. However, the important point is to think about keeping safe, have a plan and stick to it. Further information is available in ***Appendix 2: Websites and further information.***

Harassment and bullying

Bullying is behaviour that may take the form of actions or comments that are offensive, which are intended to humiliate, undermine, demean or injure the recipient. It may target an individual or group of individuals and is a form or abuse that may be explicit and therefore obvious, or it may be insidious, an experience recognised only by the recipient and harder to notice by others. Bullying may be vertical (i.e. between managers/supervisors and staff) or horizontal (i.e. between colleagues). Clients may also experience bullying by professionals. While bullying may involve a misuse of power and be committed in the workplace by a manager, supervisor or senior colleagues (sometimes known as downwards bullying), it should be borne in mind that it is not uncommon for senior staff to be bullied by those whose work they oversee.[7] What can be legitimately classified as bullying may take into account the particular personal sensitivities and characteristics of the person suffering the alleged bullying.

Harassment can be defined as actions or comments that are unwanted and which may be related to age, disability, gender reassignment, race, sex, sexual orientation, religion or belief or any other personal characteristic of the recipient. Harassment occurs when someone engages in unwanted conduct in relation to the aforementioned characteristics and that conduct has the purpose or effect of violating the other person's dignity or creating an intimidating, hostile, degrading, humiliating or offensive environment for the other person.

The Society is a charity and bound by its objects which do not include providing direct assistance to individual psychologists in these situations by offering advice. Psychologists with concerns over the above behaviour should seek the support of their supervisor, line manager or other appropriate senior staff member, accredited trade union workplace representative or human resources department. Further information is available in ***Appendix 2: Websites and further information.***

Whistleblowing

Whistleblowing is the disclosure of wrong doing (beyond normal managerial channels) and is important as it is a critical way not only of seeking justice for the individual or individuals affected, but also of developing inside information within organisations about incorrect or unfair practices,[8] thereby increasing the evidence required for corrective action to take place.

A whistle-blower is protected by law (the Public Interest (Disclosure) Act 1998) if:

1. They are a worker (this includes trainees and can include self-employed personnel servicing an organisation in certain circumstances).
2. They are acting in the public interest.
3. The disclosure relates to past, present or likely future wrongdoing which involves one or more of the following:
    - criminal offences (which may include fraudulent actions);
    - a person has failed, is failing or is likely to fail to comply with any legal obligation to which he is subject;
    - a miscarriage of justice has occurred, is occurring or is likely to occur;
    - the health or safety of any individual has been, is being or is likely to be endangered;
    - the environment has been, is being or is likely to be damaged; or
    - information tending to show any matter falling within any one of the preceding paragraphs has been, is being or is likely to be deliberately concealed.

If the individual has been victimised or if they have lost their job due to whistleblowing, the legislation provides them with the right to take a case to an employment tribunal. Whistleblowing is a complex legal area and it is important that anyone considering it considers appropriate advice, for example from an accredited trade union workplace representative or helpline. The relevant human resources department which will have a policy relating to this, or it may be appropriate to seek formal legal advice. Some organisations such as NHS Trusts have a nominated Director responsible for dealing with disclosure issues who may be contacted directly. The Society is a charity and bound by its objects which do not include providing direct assistance to individual psychologists in these situations by offering advice. Further information is available in ***Appendix 2: Websites and further information.***

Psychologists can inform on all aspects of the establishment of workplace cultural norms that promote positive managerial and leadership behaviour and can help facilitate the development of cultures that support the disclosure of inappropriate practices. Psychologists are also appropriately qualified to support workers who have been subject to bullying or harassment or who are contemplating or indeed have already 'blown the whistle'. Whistleblowing, and even the prospect of such, can create traumatic responses in workers[9] and can lead to retaliation as a consequence. Empirical evidence highlights the link between whistleblowing and the devastating effects on health that may follow, such as depression, anxiety and symptoms relating to post-traumatic stress[10]. Psychologists are able to work with affected employees and in a consultative capacity with organisations to manage work-related stress disorders caused by these incidents of bullying, harassment and whistleblowing to lessen the risk of absenteeism and to facilitate a return to work following a period of absence. Further information is available in ***Section 8: How to respond when things go wrong.***

2.2 Working in the digital age

Digital media continues to advance in terms of choice and functionality. It is becoming increasingly common for psychologists in particular when working with clients to make use of the internet and/audio-visual technology. These technologies require the psychologist to ensure that the network used is as secure as reasonably possible and, as far as is feasible, assures privacy to their clients.

There can be no guarantee of security when using the internet, and voice over internet protocol (VOIP) services such as 'Skype' or 'FaceTime' are no different, as they use the same data infrastructure as the rest of the internet.

Most, if not all, VOIP systems encrypt the voice into waveforms during digital transit across the internet, and it would be impossible to eavesdrop on these data packets in real time. However, the information is potentially vulnerable to eavesdropping/compromise before encryption by the speaker's system, and after decryption by the listener's system. This will depend upon the security measures in place for the end user's (speaker and listener) own networking infrastructures, be that a company, institution or home user. If an end user's computer has been compromised by any form of malware, then there will be a risk of eavesdropping, data theft and/or denial of service.

The risk for eavesdropping on VOIP systems is no more or less than that of traditional analogue phone systems, and both would require specialist knowledge, equipment and software to be achieved. However, it is recommended that only fit-for-purpose VOIP systems are used, and that public networks, such as Social Media sites, are avoided for VOIP communications. Further information is available on the ***Society website: http://beta.bps.org.uk/Practice-Guidelines***.

Some employers may have their own rules about which media are acceptable to use. The USA has the Health Insurance Portability and Accountability Act (HIPAA) which sets standards for security for electronic data. There is no such provision in the UK to date, and so psychologists must satisfy themselves that any media used to communicate personal data is secure. This is a rapidly changing area and so technology-specific guidance has not been provided in this document. Further information is available in ***Section 7.1: Information governance*** and ***Appendix 2: Websites and further information.***

The use of online 'Apps', computer assisted decision-making and artificial intelligence in psychological practice and research is evolving rapidly. When recommending or using computerised systems psychologists should pay due regard to peoples' health, wellbeing and safety being mindful of Clinical Safety Evaluations, Medical Device Evaluations and other relevant guidance such as NICE.

Use of social media

Many psychologists are using social media, networking sites or blogs to communicate with friends, family, professionals, colleagues and clients. This specific guidance therefore addresses the use of social media by psychologists, and provides practical advice for using them responsibly. Further information is available in ***Appendix 2: Websites and further information.***

Psychologists should:

- Remember that social networking sites are generally public and permanent. Once something is posted online, it remains traceable even if it is later deleted.
- Keep their professional and personal life as separate as possible. This may be best achieved by having separate accounts for work-related communications to those for friends/family.
- Consider whether, in their context of practice, it is appropriate to accept 'friend' requests from current or past clients, if necessary, decline the request via more formal means of communication. It is highly unlikely to be appropriate to accept in a clinical or forensic context.
- Be minded to act responsibly at all times and uphold the reputation of the profession, whether identified as a psychologist or not on the social media platform.
- Be aware that social networking sites may update their services and that privacy settings can be reset to a default that deletes personalised settings.
- Remember that images posted online by family or friends may be accessible, as they may not have set privacy settings as tightly.
- Be minded that social networking sites can make it easier to engage (intentionally or unintentionally) in professional misconduct.
- Report the misconduct of other psychologists on such social networking sites to any relevant parties (such as the employer or the HCPC).
- Be aware of their employer's social media policy.

Psychologists should not:

- Establish inappropriate relationships with clients online.
- Discuss work-related or confidential issues online in any non-secure medium.
- Publish pictures of clients online, where they are classified as clinical records.
- Use social networking sites for whistle-blowing or raising concerns.
- Post defamatory comments about individuals or institutions. Defamation law can apply to any comments posted on the web, irrespective of whether they are made in a personal or professional capacity.

2.3 Working for the court

Psychologists may be asked to act as professional or expert witnesses in court. The main difference between an expert witness and an ordinary witness (i.e. a witness to fact), is that the former are able to give an opinion, whereas ordinary witnesses can give only factual evidence. A professional witnesses' remit can cross the boundary of both fact and opinion.

Psychologists are responsible for ensuring they are sufficiently competent and expert in offering an opinion. It is not appropriate for trainee or assistant psychologists to act as expert witnesses. Indications of competence in respect of the knowledge required by the court, and expertise within a specialised field, may include:

- qualifications and/or degree(s) in the areas(s) in question;
- a number of years of post-doctoral/post-qualification experience;
- academic, professional and scientific publications in relevant areas;
- demonstrations of professional practice, competence, specialist knowledge and expertise with a bearing upon the issues in the case; and
- current experience in applying psychology in the area of claimed expertise.

It follows that a psychologist with trainee or assistant status is unlikely to have the necessary experience and qualifications to be retained as an expert witness by a legal firm. However, trainees or assistants who have written reports on individuals in the course of their employment may be required to give evidence (for example, at a tribunal). If so, they should bear in mind that only qualified psychologists should give evidence of opinion, and that their supervisor is responsible for the professional quality of their work in this situation as in all others.

Psychologists instructed as experts need to ensure that they can provide an independent and impartial opinion, and that their independence is clear to all. Any potential conflicts of interest should be made explicit and should be reported as soon as they arise. This can extend to being asked to provide an expert report on someone the psychologist is providing with therapy as an 'Applicant', 'Claimant' or 'Complainer'. This dual relationship is an unacceptable conflict.

When lawyers seek to introduce expert psychological evidence, it is the judge in the case who decides whether an individual has the requisite expertise to give evidence with the potential to be relevant to the case. The judge also decides whether what the expert asserts is relevant and, therefore, admissible in law.

Expert evidence in civil court proceedings is governed by Part 35 of the Civil Procedure Rules 1998, and its associated practice direction. This rule makes clear that an expert's overriding duty is to help the court on matters within their expertise and that this duty overrides the expert's duty to the person from whom they are receiving instructions. Any report must be written in accordance with the criteria in Practice Direction 35.

Further information is available in ***Society documents: Psychologists as Expert Witnesses: Guidelines and Procedure*** and ***Psychologists as Expert Witnesses in the Family courts in England and Wales.***

2.4 Working for defence and security organisations

Psychologists may work with defence and security interests in many different capacities. This may include supporting military or security personnel to perform their roles through the development of skills and behaviours, supporting the mental health and wellbeing of people affected by threats, activities and events in this context, and offering advice and consultancy. It is also UK Defence practice to enlist uniformed psychologists for roles associated with psychology. However, in general, psychologists in defence will be in a civilian role and therefore not under military command.

While there is a strong sense of common culture within the defence and security sectors, there are also important variations. For example, each of the armed forces has its own organisational culture resulting in different attitudes and behaviours. There are also differences within different sectors of each organisation. All these differences are very important to the individuals concerned, forming a large part of their sense of identity.

Psychologists working with these populations should ensure they investigate and acknowledge cultural differences, particularly when working with other national cultures.

They should also take careful account of the environments in which people are living and working. Psychologists can be working with civilians and/or members of the armed forces who are operating in life threatening environments and are required to make decisions under extraordinary pressure. It is usually invalid to extrapolate from behaviour in benign conditions to behaviour under threat, hardship and stress.

3. Who psychologists work with

3.1 Working with Experts by Experience

In relevant services it is best practice for psychologists to work collaboratively with clients and Experts by Experience in developing and delivering all aspects of psychological services. In mental health, the Government is committed to shared decision-making and the principle 'no decision about me without me'[11]. This applies from work with an individual client through to changes in government policy relevant to the services provided by psychologists. Psychologists should develop services, policies and guidelines in collaboration with the people who use their services.

In professional practice it is important and helpful to work collaboratively with clients and, where relevant, others in order to ensure that the application of psychological research and theory is understood by and adapted appropriately to the client group and context, which may differ from the populations on which the research was based.

3.2 Working with assistants/interns

Many graduate psychologists take up assistant psychologist positions on either a paid or an unpaid basis.

The following (non-exhaustive) list provides examples of activities which can be carried out by assistant psychologists/interns. This list can guide those who are working as assistant psychologists/interns to request or refuse a task or assignment, as well as assist those who are practising and supervising to observe boundaries and limitations:

- research, audit and service evaluation;
- literature searches, developing and maintaining training packs, information leaflets, libraries of equipment, and other tasks necessary to the efficient running of the service;
- assessment of individuals and groups, for example, direct observations, formal psychometric testing, semi-structured interviews, and writing appropriate reports;
- delivery of interventions with individuals, groups and organisations;
- undertaking supportive work with carers, family members, employers, human resources professionals, team members, health staff and other professionals;
- delivering training for other professionals (if and when competent to do so); or
- promoting applied psychology services by providing relevant information to referrers, commissioners and others.

An assistant psychologist/intern should not be employed to:

- substitute for qualified applied psychologists; or
- undertake solely administrative or clerical duties for which a clerical assistant should be employed.

In occupational settings, the issue of appropriate supervision and guidance is of particular importance when the needs of individuals and organisational demands need to be balanced. Appropriate mechanisms need to be in place to ensure that no assistant psychologist/intern is, for instance, put in a position where they have to design or decide on any materials or processes which could have a potential harmful impact on individuals or groups or to an organisation (such as potential loss of profit or revenue).

In clinical and forensic settings, there are some additional limitations, related to the clear delineation between qualified and assistant psychologist/intern, as follows:

- An assistant psychologist should carry out only prescribed interventions with individuals or in groups, and should write reports only when under close supervision of the primary, qualified psychologist. Any report should be signed as having been written 'under the supervision of' followed by the name, registration status and job title of the qualified psychologist.
- When an assistant psychologist is called to give evidence in a legal setting, such as a tribunal, the qualified psychologist remains responsible for the professional quality of the assistant's work. This means the qualified psychologist should attend the hearing also, as there may be questions which an assistant cannot answer. Both should bear in mind that an assistant is not qualified to give evidence of opinion.
- An assistant psychologist should not undertake tasks in areas where there is not a competent supervisor.
- An assistant psychologist should not carry out the duties of a care assistant.

The managing or supervising psychologist has a responsibility to ensure that assistant psychologists are not given work to do that is over and above their level of competence. Further information is available in ***Society Document: Applied practitioner psychologist internship programmes and unpaid voluntary assistant psychologist posts.***

3.3 Working with trainee psychologists

The Society's standards related to working with trainees across the domains of applied psychology are set out in the Standards for accreditation of training programmes. These set out: the required core competencies that trainees need to develop, the curriculum and assessment requirements that programme providers need to deliver against, and the requirements of supervised practice; expectations around trainees' understanding of and ability to work ethically and legally; selection and recruitment of trainees; personal and professional development of trainees whilst in training; academic staffing and leadership for accredited programmes; and expectations in relation to quality management. Psychologists working with trainees as practice educators should familiarise themselves with these standards and adhere to them in their work with trainees. Further information is available on the ***Society Website: http://beta.bps.org.uk/Practice-Guidelines.***

3.4 Working with multiple clients

Psychologists will sometimes be in situations where their client will not be one clear individual or group, for example, a psychologist may be employed by an organisation to

provide assessment or psychological support for employees. Psychologists need to consider and be mindful of the demands that this might place on their ethical practice and how this might lead to conflicts of interest.

Identification of the following client hierarchy may be considered[12,13]:

- Primary client – the person or persons with whom the psychologist is interacting directly: the recipient of a psychological service.
- Commissioning stakeholders – the organisation or overall commissioning body that has sought the psychologist.
- Others affected by the primary client's actions – the customers of the organisation or service, or the personal acquaintances, friends and family of the primary client. In some circumstances, this will be the general public or larger groups interested in the outcomes of the intervention.

The psychologist's role will be mainly to the primary client and then the commissioning stakeholder. It is paramount that issues around boundaries and sharing of information are made explicit and addressed appropriately through a clear contracting agreement. Further information is available in ***Section 3.5: Working with other professionals, Section 5: Making and maintaining agreements*** and ***Section 7: Managing data and confidentiality.***

Within each of the levels of the hierarchy, varying allegiances to associates (friends, family, acquaintances, colleagues) will need to be attended to, as will consideration of the impact of professional activity on the reputation of the profession and all those concerned.

3.5 Working with other professionals (including in multi-agency settings)

In order to meet the complex needs of clients fully, psychologists will often be required to work collaboratively with other professionals from their own or other agencies.

Such collaborative working will be for the benefit of clients and/or the promotion of the safety and protection of the public or the benefit of the organisation, and is required by national policy and legislation in a number of areas in which psychologists work. Engaging in partnerships drawing on a wide range of services and agencies enables psychologists to address identified community issues with the optimum use of resources.

Where appropriate to their context of practice, and consistent with the requirements of psychological practice, psychologists should:

- Work together with colleagues to develop a shared view of the aims and objectives of work at all levels. They should respect the professional standing and views of other colleagues and commit themselves to joint working.
- Make it clear to other professional colleagues what can be expected of them in collaborative work, the work that will be done, and the point at which the work will be terminated.
- Ensure that there are explicit agreements about information-sharing and confidentiality and its limits, and that these are adhered to.

- Practise and encourage in others full and open communication with colleagues/ agencies to support effective collaboration within the boundaries of the agreed limits on information-sharing and confidentiality,
- Demonstrate their commitment to involving clients in multi-agency work, finding ways to engage them and retaining the central principle of better outcomes for clients as the rationale for multi-professional and multi-agency work, as long as this is consistent with public safety.
- Be sensitive to the effects of clients receiving contradictory advice from different professionals or agencies and should work towards a co-ordinated view wherever possible.

3.6 Boundaries in professional relationships

Psychologists seek to establish good relationships and trust with their clients, other professionals, organisations and the community. They are aware of the complexity of professional relationships and the need to observe their boundaries. Multiple relationships occur when a psychologist is in a professional role with a client or colleague and at the same time is in another role with the same person or group e.g. as a supervisor, sports club member or co-author in a publication or where a psychologist is asked to work at a school where their child is a pupil.

Psychologists should:

- Ensure that the relationship reflects the appropriate context within which the practice is taking place.
- Be aware of the issues of multiple relationships and professional boundaries which may lead to (real or perceived) conflicts of interest or ethical considerations.
- Clarify for clients and other relevant stakeholders when these issues might arise.

When acting as leaders in practitioner or managerial roles, psychologists should maintain an awareness of the importance of respect for boundary and power issues within leadership relationships. In particular, an awareness of the possible abuse of these relationships should be maintained at all times. It is important that psychologists explicitly define the boundary of the relationship and negotiate and respect the responsibility that each holds in relation to it. Where psychologists are in a position of power/leadership with individuals, it is particularly important that they exercise caution and consider the possible issues which may arise from developing a personal relationship with these individuals. It may be necessary to seek further supervision where appropriate, with additional peers as necessary.

Psychologists have a duty of care towards their clients, who may be vulnerable, and should maintain a professional emotional distance from clients, services users or relatives and should not enter into an intimate or sexual relationship with any clients, service users or relatives they come into contact with as part of practice. Psychologists should also be aware that their duty of care can continue after a client practitioner relationship has ended.

As far as is reasonably practical, psychologists should not enter into a professional relationship with someone with whom they already have, or have had, a close personal

relationship. This includes family members and friends. Where there is no reasonable alternative, such as a lack of availability of other professionals, and it is acceptable in the particular context of practice, the psychologist should make every effort to remain professional and objective while working with the individual they know or have known. In such circumstances, at the earliest possible opportunity, this should be disclosed and discussed with a manager, where there is one, and supervisor and a note should be made in client records.

A range of psychologists work with people who initially have accessed the services in a dependent position, and have then transitioned to becoming partners and colleagues in service and policy development and design. The nature of the work becomes more collegiate and the psychologist holds multiple roles including facilitating participation, adapting communication and advocacy.

3.7 Working with children and young people

When seeking to work with children and young people, psychologists should consider how they can develop ways of communicating with the child or young person that will be most effective in ensuring they can express their views and feelings.

In most instances psychologists will use their specialist professional training and experience working with children, young people and families in order to understand the developmental needs of the child or young person in question; where a psychologist does not have specialist training that has included children and young people then there would be an expectation that advice or supervision should be sought before working with a child, young person, or their family. Similarly, work with children, young people and their families should take account of wider systemic factors outside of the child or young person; this will usually involve the child's family and may also include their school, and other settings.

As with adult clients, there can be misunderstandings and confusions about the role of a psychologist, the nature of the work being undertaken, and the possible outcomes of the work. It is essential to ask the children and young people about their understanding of what is happening on a regular basis (this may be appropriate at each session) and address any confusion that has arisen.

When working with children and young people, psychologists are advised to ensure that they have ascertained who has parental responsibility and that those with parental responsibility are aware of their planned involvement, if this is appropriate. Psychologists working with children, young people and families need to be aware that young people who are deemed to be competent to make their own decisions: 'Gillick competent'[14] can give their own consent to involvement with a psychologist, and that if a young person gives consent under these circumstances, then parental consent is not required. Similarly, a young person who is 'Gillick competent' can give consent even if parents have declined to give consent; such young people can also ask that parents are not informed of any involvement, and this should be respected by the psychologist; an example here would be in a school setting where a young person may give their own consent to see a psychologist

and may ask for parents not to be informed. Psychologists also need to be aware that where separated or divorced parents share parental responsibility, one parent can give consent.

3.8 Working with people with intellectual disabilities and impaired cognitive abilities

Psychologists are likely to work at some point with a range of people whose cognitive abilities are either temporarily or permanently altered, either by organic or developmental changes. Appropriate assessment of the abilities and skills is required, so that adaptions can be made to further interventions, treatments or management. The implications of the cognitive abilities on the person, their family and the reason for psychology involvement, will need to be considered.

Psychologists working with people with intellectual (learning) disabilities will need to consider adaptations to their approach to ensure the service they are offering is clearly understood, and is adapted to the individual's preferences, strengths and needs. This can include considering adaptations to oral or written communication, psychological assessment, intervention, and outcome evaluation.

Psychologists will need to be flexible and to make reasonable adjustments to their usual practice to ensure an appropriate service is offered. Psychologists should ensure their work is person-centred and respectful of the individual's needs, whether that work involves working with the individual with intellectual disabilities directly, or whether it also includes, or even may predominantly involve, working indirectly with family, carer or professional systems around the individual.

Psychologists will need to be mindful of the range of complex factors that often affect people with intellectual disabilities (e.g. communication needs, poorer mental and physical health outcomes and healthcare service experiences, unemployment, disempowerment, social isolation and exclusion, including experiences of bullying, abuse and hate crime, being overrepresented in the prison population, among others) and, therefore, the specific policy and practice guidance that applies. Further information is available in ***Section 4.2: Safeguarding adults at risk of harm*** and ***Section 6.3: Informed consent with people who may lack capacity.***

3.9 Working with detained people

Where clients are detained involuntarily there will always be a legal framework within which professionals must practise, and they should be aware of how their work fits into that framework. Involuntary detention is not only covered by professional rules and national legislation, but also by international agreements.

Psychologists should be aware that having the approval of one's employer is not necessarily a guarantee that practice is either ethical or legal, as described for example in the Hoffman report[15]. Where practitioners have doubts about the legal or ethical acceptability of employer demands, they should seek advice from an accredited workplace trade union representative, a human resources department, or appropriate helpline. They should

follow their organisation's guidelines on raising concerns at work. Seeking advice outside the immediate setting is helpful as colleagues within the workplace may be subject to the same pressures as they are.

Under the headings below, the role of the practitioner can be seen to be key to the way that detained persons are understood, and this can have a great impact on the way that their cases are handled by the detaining authority. The practitioner therefore has considerable power, whereas the client has very little. This power imbalance should always be borne in mind by practitioners dealing with detained persons. They should also bear in mind that the imbalance can be implicit as well as explicit.

Prisoners

Putting psychological pressure on detained persons to obtain a confession to an offence is illegal under the UN Convention on Torture[16]. In this context, 'psychological pressure' could well include such things as telling indeterminate-sentence prisoners who maintain innocence that they are unlikely to be released unless they engage with an intervention that relies on acknowledgement of guilt. Decisions about release are not the role of the practitioner, unless they are directly involved with, or are a member of the release authority, with a delegated role in the formal decision-making process. An approach to engagement such as this would not be considered beneficial to the client. However, those instructed by any party to the formal Parole Board decision-making process may properly be asked to give an opinion on suitability for release.

Practitioners dealing with detained offenders who have committed violent or sexual offences should guard against being morally judgemental. It is routine for practitioners in this field to encounter offenders who have committed very unpleasant acts with whose victims they can readily identify. Psychologists should be mindful that their own views about a client do not impact on their work.

Care should be taken when working with detained persons whose literacy is poor or whose first language is not English, and who cannot read a report which has been written about them. Even clients who are literate in English will probably not be familiar with psychological terminology, and may need considerable time to read and fully digest a report. People who are detained can also have cognitive challenges or intellectual disabilities which might make this process more difficult.

Persons detained under immigration legislation

Detained people may be afraid of raising a particular topic in case it is misunderstood, or too embarrassed because of cultural standards. For example, in some cultures it is difficult or unacceptable to discuss sexual matters, but sexual violence has been suffered by many asylum seekers in conflict zones, and some discussion of it may be essential in assessing their case. Even within the same culture there can be considerable generational differences.

Psychologists should guard against unwarranted interpretations of psychological evidence by commissioners or authority figures. For example, reporting that someone's story shows inconsistencies may give the impression that they are lying. This may be the case, but inconsistencies alone are insufficient proof of this. It is commonplace for evidence to be

inconsistently reported when people have been through traumatising experiences in areas of conflict, as is often the case with persons detained under immigration legislation.

Practitioners should take particular care in dealing with detained persons whose first language is not English. The opportunities for misunderstanding in both directions should be obvious, and in many cases the correct procedure will be to interview with the help of an interpreter. Failing to use interpreters when it was clearly appropriate to do so could inappropriately compromise the quality of the psychologist's work.

Mental Health Detentions

Mental Health Act 1983 as amended 2007 (England and Wales)
Under the Mental Health Act (MHA) a person can only be detained for treatment if that person is suffering from a mental disorder of a nature of degree that makes it appropriate for them to receive medical treatment in hospital. In the Act 'mental disorder' is defined as 'any disorder or disability of mind'. This definition is very broad but the *Code of Practice* provides guidance on clinically recognised conditions that fall within its meaning. Major categories of mental illness (e.g. affective disorders, schizophrenia and organic mental disorders) are included along with personality disorders, autistic spectrum disorders and learning disabilities (the latter only if accompanied by abnormally aggressive or seriously irresponsible behaviour). Dependence on alcohol or drugs is not considered a mental disorder under the MHA.

In the Act, all 'medical treatment' including psychological interventions is for the purpose of alleviating, or preventing a worsening of a mental disorder or one or more of its symptoms or manifestations. The medical treatment must be required for the health and safety of the client or for the protection of others. This means that the primary purpose of psychological interventions offered and provided to detained persons has to be to reduce the risks that their mental disorder presents to the detained person or others; as once those risks are reduced or minimised the client will no longer require detention and can progress to a less restrictive environment. This requirement points to the importance of an individualised formulation of a client's treatment needs that includes a careful assessment of the risks to self and others (see section on Risk Assessment, p.32).

Under the MHA appropriate medical treatment must be available. This is described as the 'appropriate medical treatment test' in the *Code of Practice*. Such treatment must have the *purpose* of alleviating or preventing a worsening of the disorder or its symptoms or manifestations, even if it cannot be shown in advance that the treatment is likely to have an effect for a particular patient. Thus, appropriate medical treatment need not be likely to achieve those purposes. That is, purpose is not the same as likelihood. The nature and degree of the patient's mental disorder and all the patient's particular circumstances are all relevant to whether the treatment is appropriate.

The appropriate medical treatment test is designed to ensure that patients are not detained for treatment unless they are actually to be offered appropriate treatment for their mental disorder. Thus, the MHA requires only that appropriate treatment is available to a detained patient. The patient's refusal to accept treatment is not an obstacle to detention, so long as appropriate treatment is available.

This has particular relevance for psychological therapies. The Code at chapter 23.20 states:

> *In particular, psychological therapies and other forms of medical treatments which, to be effective, require the patient's cooperation are not automatically inappropriate simply because a patient does not currently wish to engage with them. Such treatments can potentially remain appropriate and available as long as it continues to be clinically suitable to offer them and they would be provided if the patient agreed to engage.*

Whilst the availability test of appropriate medical treatment applies to psychological interventions in the same way as for other forms of treatment, it is important for psychologists to avoid placing pressure on clients to participate in such treatment. In order for there to be an effective therapeutic alliance there needs to be trust and this only develops in the absence of coercion. Psychological therapy works when the client decides they are ready for therapy and freely consents to it. There is an inevitable power differential in favour of the clinician. Thus, every attempt should be made to emphasise patient involvement and choice and to avoid coercion in a manner consistent with the *Code of Practice* empowerment and involvement and respect and dignity principles. Further information is available in ***Section 6: Obtaining informed consent.***

The Mental Health Act 2007, which amended the MHA 1983, introduced approved clinicians (AC) who may be drawn from a defined group of professions, including practitioner psychologists listed in the register maintained by the Health and Care Professions Council. ACs are approved by the appropriate national authority to act as an approved clinician for the purposes of the MHA 1983. Responsible clinicians (RC) are ACs who have overall responsibility for an allocated patient's case. The Code of Practice at chapter 36.3 says that a patient's RC should be the available AC with the most appropriate expertise to meet the patient's main assessment and treatment needs. At chapter 36.5 the Code says that where psychological therapies are central to a patient's treatment then it may be appropriate for a professional with particular expertise in this area to act as the RC.

Chapter 39 of the *Code of Practice* provides guidance on the circumstances in which potential conflicts of interest may prevent designated professionals from making an application for or recommendations supporting a patient's detention or guardianship. The potential conflicts of interest dealt with in the Code involve financial, business, professional and personal issues.

The Mental Health (Scotland) Act 2015

This act, together with the Mental Health (Care and Treatment) (Scotland) Act 2003 sets out the law for detaining patients and restricting patients. For patients to be detained, this has to be considered by the Mental Health Tribunal for Scotland. This applies, for example, to those detained in the NHS who are not subject to a court (forensic) decision.

Restricted patients are 'detained in hospital under a compulsion order with a restriction order'. They have usually committed an offence punishable by imprisonment but as a result of mental disorder are not imprisoned but ordered to be detained in hospital for treatment, without limit of time. They are dealt with through a programme of treatment and rehabilitation – the aim being to prevent recurrence of offending by dealing with the mental disorder'.

Risk assessment

When dealing with detained people seeking release, such as parole applicants or patients seeking release from a mental health tribunal, risk assessment (usually for violence risk) will be a prime consideration. Psychologists should bear in mind that risk assessment is not prediction. Risk assessment instruments are rarely more than about 70 per cent accurate when predicting reconviction and many items on commonly used risk-assessment schedules are of poor predictive value.[17] Psychologists should also bear in mind that risk-assessment instruments are better at identifying low-risk than high-risk individuals[18],[19]. A statement of risk is not a prediction about an individual, but a statement based on the behaviour of a criterion group with which that individual is being compared. Risk is statistical by its very nature, and the value of such comparisons depends upon the individual's similarity to the criterion group upon which the risk assessment instrument was developed. Accuracy may be greatly reduced if the similarity is low[20]. It may be better to think of risk assessment as a process of identifying those risk factors which need to be monitored and controlled if supervision of the individual is to be reduced or withdrawn.

3.10 Working with people who are, or would like to be employed

Psychologists are sometimes commissioned to deliver psychological assessment or training with employees and potential employees. Psychologists should take particular care over the advice provided in follow-up reports, as employers are not trained professionals and may misinterpret advice or psychometric testing results. For example, citing a reading ability level using age is misleading, and could be interpreted as incompetent for the role, when in reality the role does not require a high reading level or a reasonable adjustment could be provided.

Similarly, psychologists should ensure that the tools they are using to assess competence or suitability are appropriate for the role, and have good reliability and validity. Any tools devised by the psychologist are likely to be interpreted by the employer as professional and authoritative, where there is ambiguity or multiple interpretations, this must be made clear, so that decisions about peoples' employment are not made in error.

There are people who work or who would like to work, who may experience cognitive difficulties caused by a range of factors, for example intellectual disabilities, dementia, acquired brain injury. Sometimes this information is known and needs to be considered when assessing and advising. At other times, this possibility of a cognitive or intellectual impairment needs to be considered. The impact of this can be far reaching, in terms of ongoing or future employment, access to benefits and of course associated psychological adjustments for the person and the people around them. Further information is available in ***Section 7: Managing data and confidentiality*** and ***Society Document: Psychological Assessment of Adults with Specific Performance Difficulties at Work.***

3.11 Working with cultural difference

It is expected that all psychologists will have the necessary skills and abilities to work with all sections of the community.

Psychologists need to be aware of stereotypical beliefs and assumptions which manifest in thinking about culture and ethnic groups. Psychologists should bear in mind the history of racism and the early development of Western psychology[21] and culturally biased testing in favour of white, middle-class children. Psychologists need to recognise that multi-ethnic groups are not homogenous groups and there are wide regional and local differences among these groups which can be split by language, dialect and regional variations. Each ethnic community has a distinct identity and religious focus may also vary within and across communities.

Race is not a biologically meaningful concept to apply to people, and even the artificial divisions between the so-called racial groups are nebulous and unstable, biologically, socially and physically.[22]

Psychologists need to understand the discrimination suffered by people from diverse and/or minority ethnic and religious backgrounds as a result of:

- the interchangeable use of the terms race, culture and ethnicity leading either to the perception of black and minority culture, race and ethnicity as unitary or an assumption that knowing about these cultures solves the problem of equality, fairness and availability of services;
- the maintenance of the colour-blind approach in service where 'one size fits all', resulting in a lack of formal recognition of the varied diverse needs as well as these needs being ignored, unacknowledged or assumed to be the same;
- the lack of appropriate culturally relevant psychological therapy available to certain Black and Minority Ethnic (BME) communities;
- being discriminated against on grounds of 'special' needs, effectively considered as 'cultural pathology'; and
- experiencing instances of indirect, subtle, or unintentional discrimination often called 'micro-aggressions'.

It would be expected that all practising psychologists should develop a productive working relationship with culturally and linguistically diverse groups of people by:

- avoiding different types of biases and find new ways (verbally and non-verbally) to build rapport and respect;
- using and working with trained interpreters in assessment, formulation and intervention work as well as research work;
- being aware of the impact of culture, ethnicity and religion in assessment, formulation and intervention processes and the use of norm-referenced tests which do not include minority ethnic groups as part of their standardisation;
- pre-assessing and pre-incorporating ethnic identity (including its fine gradations, region, class and generation) which can have impacts on processes and outcomes of psychological work;
- acknowledging their own ethnocentricity and possible underlying socially conditioned prejudice to people who are 'different'; psychologists need to acknowledge that people can change, irrespective of their differences and psychological distress;
- relooking at current models of mental health which traditionally reflect Western

constructions, and incorporating other world views of psychological wellbeing; and
- understanding and respecting the different concepts of health and illness that exist within different ethnicities, including newly arrived people from Europe and refugees from Syria, Turkey, Somalia etc.

Psychologists need to: address the different life situations and life circumstances experienced by users who wish to use mental health services; hear their voices based on their personal experiences; and act and respond accordingly in a human way.

3.12 Working with people of faith, religion and spirituality

In working with clients who hold a variety of values and religious and spiritual beliefs which may be different from their own, psychologists should consider the following:
- Psychologists should respect clients' values and spiritual beliefs and need to be mindful that their personal beliefs should not be an impediment to engaging with the client.
- Spiritual beliefs are very often beneficial to the client's wellbeing and may be helpful to be incorporated into any intervention to achieve a positive impact where appropriate.
- In some circumstances the client's faith belief may be harmful or detrimental to themselves or others.

3.13 Working with sexual and gender minorities

Psychologists are committed to the fair treatment and inclusion of people who are intersex, people who do not identify as heterosexual and/or people who do not identify with their natally-assigned sex. This section provides guidance to address specific issues in support of these heterogeneous populations. In these guidelines we use the term 'sexual minority(ies)' to refer to individuals whose romantic attraction or sexual attraction is other than heterosexual (different from the majority in the surrounding society), and the term 'gender minorities' to refer to transgender, genderqueer and intersex individuals.

When working with gender and sexual minorities, psychologists are encouraged to:
- remember that sexual and gender minority identities are not indicative of mental health disorders;
- understand that attitudes towards sex, sexuality and gender are located in a changing social, cultural, and political context, and to reflect on their own understanding of these concepts and how it may impact their practice;
- reflect on the limits of their practice when working with certain sexual and gender minority clients, and to consider appropriate referral and training when necessary;
- understand how social stigmatisation (e.g. prejudice, discrimination and violence) poses risks to gender and sexual minority clients;
- consider engaging with the wider socio-political context regarding sexual and gender minorities in order to reduce social stigma;
- be knowledgeable about the diversity of sexual and gender minority identities and practices;

- use the preferred language of the sexual and gender minority individuals;
- understand the unique and particular circumstances and challenges facing clients with diverse gender and sexual identities and practices;
- understand the diversity of forms of relationships and families in gender and sexual minority clients;
- be aware of the potential challenges facing sexual and gender minority clients in their relationships and families;
- be mindful of the intersections between sexual and gender minority and socio-cultural/economic status;
- recognise the particular challenges experienced by gender and sexual minorities with physical and/or mental health difficulties;
- recognise the diversity of developmental pathways for sexual and gender minority children and adults;
- recognise the needs and issues of young people from gender and sexual minorities, and their particular vulnerabilities;
- support the self-determination of their clients in the development of their identities and practices; and
- avoid attempting to change gender or sexual minorities on the basis that they can be 'cured' or because of stigmatising theory, personal, religious and/or socio-cultural beliefs.

Working with racially and ethnically diverse Lesbian, Bisexual, Gay, Trans*, Queer (LGBTQ) populations

Black and minority ethnic (BME) LGBTQ people have to negotiate between the values and beliefs of the mainstream and minority ethnic cultures. Cultural differences in norms, beliefs, and values can be a source of psychological stress[23],[24],[25]. There may be no particular sexual and ethnic minority group to which a BME LGBTQ person can anchor their identity and obtain acceptance and support. This may be a particular issue for BME LGBTQ youth who are exploring their sexuality and sexual identity.

When offering psychological services to racially and ethnically diverse LGBTQ populations, it is not sufficient for a psychologist simply to identify the racial and ethnic identity and background of the client. Ethnic minority status can complicate and exacerbate the issues, challenges and difficulties the client experiences. The client can be affected by the way their ethno-culture community view and understand sex, sexuality and gender. The issue of racism within the LGBTQ community is also an important issue to consider[26],[27],[28],[29]. Sensitivity to the complex dynamics associated with factors such as cultural values about gender roles, religious and procreative beliefs, degree of individual and family acculturation, and the personal and cultural history of discrimination or oppression is also important. All of these factors may have a significant impact on identity integration and psychological and social functioning[30],[31],[32],[33],[34].

Further information is available in ***Society Document: Guidelines and Literature Review for Psychologists Working Therapeutically with Sexual and Gender Minority Clients.***

3.14 Working with people who may be socially excluded

Social exclusion refers to the extent to which individuals are denied access to the prevailing social system and the right to participate in key areas of social, economic and cultural life. This exclusion occurs due to constraints and restrictions rather than as a matter of choice. Exclusion is typically a result of poverty and/or belonging to a social minority group. The impact of social exclusion has been well documented and leads to the perpetuation of cycles of inequality for individuals and groups. These cycles of inequality are perpetuated in terms of income, health, opportunity, relationships and life-span. Further information is available in ***Society Document: Socially inclusive practice.***

Social inclusion is the process where the needs of all members of communities and the groups which constitute them are recognised, prioritised and met, resulting in these individuals feeling valued and respected. Promoting social inclusion is a broader task than promoting equality and tackling discrimination and stigma. It requires psychology professionals to address wider structural issues in society which maintain excluding processes and power differentials.

The range of individuals and groups who may experience disadvantage and exclusion is not limited to the protected characteristics outlined in the Equality Act. For example, people may also experience exclusion because of their age, they are a carer or are in care, they have a low income or low educational achievement, or their cognitive ability is compromised.

When working towards social inclusion psychologists are encouraged to:

- acknowledge, understand and respect the diversity of the communities in which they practise;
- make adjustments where possible and needed, to enable people to fully participate, e.g. to communication, access to services, adaptation to materials and psychological assessment and interventions;
- recognise that they have a professional duty actively to promote equality and opportunity;
- recognise the shame and distress caused by discrimination, and the impact of discrimination on wellbeing;
- acknowledge and respond to the trauma and distress caused by exclusion;
- move beyond the level of the individual and recognise that social exclusion is a structural issue, and that inclusion will be achieved only by structural changes in society and broad policy initiatives;
- acknowledge that there is a responsibility to highlight the links between structural societal factors and mental health problems;
- make employers, policy-makers, clients and the general public aware of situations where policies, practice and the distribution of resources are oppressive, unfair, harmful or illegal;
- challenge social conditions, both as individuals and collectively, that contribute to social exclusion and stigmatisation;
- make services accessible in terms of time, space, familiarity and comfort; make reasonable adjustments to services to meet individuals' needs; people need to be able

to get to places, get into places, feel welcomed to places and feel that they belong in places;

- recognise that inclusive services reflect the communities they serve in terms of the identities and diversity of the staff team;
- recognise the range of interventions that can improve clinical and social outcomes and use influence to ensure these services are commissioned;
- emphasise social outcomes and participation alongside clinical outcomes;
- maintain an emphasis on empowering clients to achieve their social goals; and
- identify natural sources of support and reciprocal relationships for individuals within their communities, and seek out opportunities to help individuals transition out of formal mental health services.

4. Safeguarding

Safeguarding means protecting people's health, wellbeing and human rights, and enabling them to live free from harm, abuse and neglect[35]. This guidance addresses safeguarding of both children and adults.

Abuse takes many forms and cuts through various domains of life. The categories below are often referred to in investigation/legislation context and are not mutually exclusive with e.g. emotional abuse featuring in the other domains of abuse. Abuse can be found across all sections of society, irrelevant of gender, age, ability, religion, race, ethnicity, personal circumstances, financial background or sexual orientation.

- Physical abuse – is the use of physical force or mistreatment of one person by another which may or may not result in actual physical injury. This could include hitting, poisoning, deprivation of food, water or liberty, rough handling or exposure to heat or cold, amongst other things.
- Sexual violence and abuse – sexual abuse is any behaviour perceived to be of a sexual nature which is unwanted or takes place without consent or understanding. Sexual violence and abuse can take many forms and may include non-contact sexual activities such as: indecent exposure, stalking, grooming or being made to look at, or be involved in the production of sexually abusive material, or being made to watch sexual activities.
- Psychological/emotional abuse is behaviour that is psychologically harmful or inflicts mental distress by threat, humiliation or other verbal/non-verbal conduct. This may include threats, blaming, controlling, intimidation or coercion amongst other things.
- Financial abuse is actual or attempted theft, fraud or burglary. It is the misappropriation or misuse of money, property, benefits, material goods or other asset transactions which the person did not, or could not, consent to, or which were invalidated by intimidation, coercion or deception. This may include exploitation, embezzlement, withholding pension or benefits or pressure exerted around wills, property of inheritance.
- Institutional abuse is the mistreatment or neglect by a regime or individuals, in settings which people who may be at risk reside in or use. Institutional abuse may occur when routines, systems and regimes result in poor standards of care, poor practice and behaviours, inflexible regimes and rigid routines which violate the dignity and human rights of the adults and place them at risk of harm. It may occur within a culture that denies, restricts or curtails privacy, dignity, choice and independence. It involves the collective failure of a service provider or an organisation to provide safe and appropriate services and includes a failure to ensure the necessary preventative and/or protective measures are in place.
- Neglect is the persistent failure to meet basic physical and/or psychological needs. It may involve a parent or carer failing to provide adequate food, clothing and shelter, failing to provide or unresponsiveness to, basic emotional needs or failing to protect from physical harm.

Psychologists are in a particularly relevant position to identify interactions or circumstances that affect health and development. This applies not only to psychologists who undertake direct work with children and vulnerable adults in a variety of settings; but also to those who work with clients, seen for instance in clinics, hospitals or prisons, who may make historical disclosures of abuse or raise concerns about child protection or the welfare of people within their families or communities. Safeguarding is thus the responsibility of all psychologists whatever their role.

4.1 Safeguarding children

The Society endorses *Working Together to Safeguard Children* – A guide to inter-agency working to safeguard and promote the welfare of children[36]. Safeguarding children is the responsibility of everyone.

The guidance defines safeguarding children as protecting children from maltreatment and preventing impairment of children's physical or mental health or development (physical, intellectual, emotional, social and behavioural). Promotion of welfare is defined as ensuring that children grow up in circumstances consistent with the provision of safe and effective care, and taking action to enable all children to have the best life chances.

Child protection within safeguarding refers to the activity that is undertaken to protect specific children who are suffering or likely to suffer significant harm. For the purposes of child protection legislation children are those who have not yet reached their 18th birthday. The child's needs are paramount, and the needs and wishes of each child be they a baby or infant or an older child, should be put first, so every child receives the support they need before a problem escalates.

The policy of Working Together is underpinned by two key principles: (a) safeguarding is everyone's responsibility and for services to be effective each professional and organisation should play their full part; and (b) safeguarding requires a child-centred approach based on a clear understanding of the needs and views of children.

Where there are concerns that a child is at risk of harm, such concerns should normally be communicated following the psychologist's work-place safeguarding protocol. Where this is not applicable, concerns about a child's welfare can be made directly to the local authority children's social care team.

Psychologists should:

- be alert to the heightened vulnerability/possible need for early intervention support for a child who: has a disability, has additional needs (including special educational needs), is a young carer, is showing signs of engaging in anti-social or criminal behaviour, has returned home from care and/or is showing early signs of abuse and/or neglect.
- be alert to heightened vulnerability where a child is in a family circumstance presenting challenges for the child, such as substance abuse, adult mental health problems and domestic violence.
- consider the potential impacts of parental/carer ill-health on the family and whether this creates any significant negative impacts or risks for children within that family;

- be aware that if an adult has responsibilities for children outside the home setting, such as working with children, their mental ill-health and/or their health more generally upon the adult's capacity to work safely;
- be aware that children within the same family can be treated differently (one child may be singled out for abuse);
- be aware/seek to understand how children can come to abuse other children;
- recognise that some professionals use their position to abuse children and vulnerable people; and
- challenge institutional abuse in its many forms.

Psychologists should be aware of situations of risk which require additional consideration, notably:

- sexual exploitation, which involves exploitative situations, contexts and relationships without the child recognising the harm on account of their age/understanding, social/economic and/or emotional vulnerability;
- internet abuse, which can involve cyber bullying, exposure to pornography or violence and exploitation of young people;
- domestic violence which may expose a child to violence directly or indirectly;
- shame-based abuse where children or young people may be physically assaulted or murdered because of bringing perceived 'shame' to their families or breaking cultural expectations of 'honour'; and
- Trafficking, any child transported for exploitative reasons is considered to be a trafficking victim, whether or not they have been forced or deceived. This is partly because it is not considered possible for children to give informed consent. Even when a child understands what has happened they may still appear to submit willingly to what they believe to be the will of their parents or accompanying adults.

Psychologists should have a knowledge and understanding of services for children in need and how to access them. Psychologists confronted with child abuse in any form should contribute to whatever actions are needed to safeguard children and promote their welfare. The needs/interests of adults should not be allowed to take precedence ahead of the needs of the child. Psychologists should work co-operatively with parents/carers unless this is inconsistent with ensuring the child's safety and ensure that the child's view is sought, heard and communicated. Psychologists should share appropriate information in a timely way, discuss any concerns and help analyse information so that an assessment can be made of the child's needs and circumstances. Psychologists should contact the children's services or social services department at the appropriate local authority (in some cases this role has been delegated to a multi-agency safeguarding hub) if they are concerned about a child or a vulnerable adult.

Managing cases of alleged historical abuse

There is a growing recognition that a disclosure of non-recent abuse may reveal current risks to others from an alleged perpetrator. Psychologists have a duty of care to their clients, and in the safeguarding of others. This may place psychologists in complex positions when trying to negotiate and balance their duties and responsibilities.

Psychologists who work with adult clients who disclose non-recent sexual abuse, should recognise that there may be current and ongoing risks posed by the alleged perpetrator to others. Not sharing concerns beyond the consulting room could mean that other children and young people could be at risk.

A client's allegations should be taken seriously, regardless of their presenting problems or mental health diagnosis.

Lack of access to children identified through familial relationships, work or volunteering roles should not eliminate concerns about risk, given opportunities for abuse to occur within communities.

It is crucial that psychologists seek advice from colleagues, particularly colleagues in safeguarding services, within the organisation and also from other agencies tasked with leading on safeguarding (i.e. social services). Psychologists working with clients without a referral and where no stakeholder agency is involved should seek advice from senior experienced colleagues on how to proceed. Psychologists need to be alert to the possibility that abuse may be organised, severe and complex.

There may be times when, in the interests of supporting a client's psychological readiness for disclosure, consultation may continue without requiring identifying details to be provided to the psychologist. It is important that a clients' lack of readiness to disclose does not become an obstacle to receiving psychological help. Further information is available in ***Society Document: Guidance document on the management of disclosures of non-recent (historic) child sexual abuse.***

Where the disclosure is made by the perpetrator of the abuse, risk assessment should be made regarding the context of the setting of the disclosure but there may be a professional obligation to disclose the criminal offence in order to safeguard other potential victims as above.

4.2 Safeguarding adults at risk of harm

The Care Act 2014 brought in new legislation regarding the safeguarding of all vulnerable adults. In some regions there is a move away from the term 'vulnerable adult' towards the concept of an adult at risk of harm.

An adult at risk of harm is a person aged 18 or over with need for care or support, who is experiencing, or is at risk of, abuse or neglect, and as a result of their needs is unable to protect himself or herself against the abuse or neglect or the risk of it. The needs referred to here may cover a variety of personal or life circumstances including (but not limited to) cognitive impairment, age, disability, illness, injury or mental health condition.

The legal context

There is no set piece of legislation for adult safeguarding. It is a mix of criminal law, case law and welfare law. The Care Act 2014, updated in 2016, brought in the first legal framework for safeguarding adults in a single act. It contains a range of regulations and statutory guidance, which form the base upon how social care will develop in the future.

It enshrines the new statutory principle of wellbeing and it makes it the responsibility of local authorities to promote wellbeing when carrying out any of their care and support functions. The act specifies the rights of those who need care and support, their carers, and the funding system for care and support. It recognises that this cannot be achieved by any single agency. Every organisation and person who comes into contact with a child or adult has a responsibility and a role to play to help to keep children and adults safe. Further information is available in ***Appendix 1: Relevant legislation.***

Modern slavery

An important area of concern is modern slavery. The Government website provides details about the government's work to end modern slavery, including details about how to refer victims into the national referral mechanism (NRM). Modern slavery is a serious crime. It encompasses slavery, servitude, and forced or compulsory labour and human trafficking. Modern slavery victims can often face more than one type of abuse and slavery, for example if they are sold to another trafficker and then forced into another form of exploitation.

A person is trafficked if they are brought to (or moved around) a country by others who threaten, frighten, hurt and force them to do work or other things they don't want to do.

A victim of slavery is entitled to help and protection from the UK Government (this is called the National Referral Mechanism), all support is provided on a confidential basis, and support to talk to the police. The National Referral Mechanism has been put in place to identify victims of trafficking and refer them to organisations that will offer help and support. Further information is available in ***Appendix 2: Websites and further information.***

Responding to concerns

Safeguarding adults means:

- Protecting the rights of adults to live in safety, free from abuse and neglect.
- People and organisations working together to prevent and stop both the risks and experience of abuse or neglect.
- People and organisations making sure that the adult's wellbeing is promoted including, where appropriate, taking fully into account their views, feelings and beliefs in deciding on any action.
- Recognising that adults sometimes have complex interpersonal relationships and may be ambivalent, unclear or unrealistic about their personal circumstances and therefore potential risks to their safety and wellbeing.

Providers' safeguarding arrangements should always promote the adult's wellbeing. Being safe is only one of many things that adults want for themselves and there can be challenges in balancing safety and freedom in a way which protects and fulfils human rights. Providers, and other professionals where relevant, should work with the adult to establish what being safe means to them and how that can be best achieved.

Care and support means different things in every case. The fundamental standard on safeguarding is that children and adults using services must be protected from abuse and improper treatment. Providers should establish and operate systems and processes

effectively to ensure this protection and to investigate allegations of abuse as soon as they are aware of them.

The standard states that care or treatment must not:

- Discriminate on the grounds of any of the protected characteristics of the Equality Act 2010;
- Include acts intended to control or restrain an adult or a child that are not necessary to prevent, or not a proportionate response to, a risk of harm to them or another person if the adult or child was not subject to control or restraint;
- Be degrading to the adult or the child;
- Significantly disregard the needs of the adult or the child for care or treatment.

The standard goes on to state that no adult or child must be deprived of their liberty for the purposes of receiving care or treatment without lawful authority.

Safeguarding Adults Boards were established to help and safeguard adults with care and support needs The Safeguarding Adult Board must lead adult safeguarding arrangements across its locality and oversee and coordinate the effectiveness of the safeguarding work of its member and partner agencies, according to the values of 'Making Safeguarding Personal' Guide 2014[37]. Making safeguarding personal is not just for people with capacity, it is just as important for people who lack capacity. The Guide specifies outcomes that people might want including to be and to feel safe, to maintain or get friends, to know that this won't happen to anyone else or to be able to protect self in the future.

The following are not outcomes:

- Harm or abuse is substantiated/unsubstantiated.
- The person is receiving increased monitoring or care.

The role of the Care Quality Commission[38] is to monitor, inspect and regulate services to make sure that they meet the fundamental standards of quality and care. The Commission works alongside Safeguarding Adults Boards and Safeguarding Children Boards to share information and intelligence where appropriate to help them identify risks. This includes providing appropriate advice and support to people at risk of radicalisation in sectors such as healthcare and education.

4.3 Terrorism and extremism

Section 26 of the Counter-Terrorism and Security Act 2015 (the Act) places a duty on certain bodies ('specified authorities' listed in Schedule 6 to the Act), in the exercise of their functions, to have 'due regard to the need to prevent people from being drawn into terrorism'. Depending on where the psychologist works, these duties may have relevance in the course of their employment. The term 'due regard' as used in the Act means that the authorities should place an appropriate amount of weight on the need to prevent people being drawn into terrorism when they consider all the other factors relevant to how they carry out their usual functions.

The current UK definition of 'terrorism' is given in the Terrorism Act 2000. In summary, this defines terrorism as an action that endangers or causes serious violence to a person/people; causes serious damage to property; or seriously interferes or disrupts an electronic system. The use or threat must be designed to influence the government or to intimidate the public and is made for the purpose of advancing a political, religious or ideological cause. People suspected of being involved in such activity must be referred to the police.

'Extremism' is defined in the Prevent Strategy[39] as vocal or active opposition to fundamental British values, including democracy, the rule of law, individual liberty, and mutual respect and tolerance of different faiths and beliefs. Definitions of extremism can also include calls for the death of members of our armed forces, whether in this country or overseas.

While it is recognised there is no single profile associated with extremism, identity is considered to be central, and risk screening is based on assessment in relation to two general pathways into extremism – criminal and non-criminal. Disengagement follows a similar process. This is a contentious area of practice. Psychologists should ensure they focus on their core role, working in a non-stigmatising way, and avoiding profiling based on characteristics such as race, religion, ethnicity or any other aspect. The psychologist should carefully weigh relevant professional obligations and seek and follow appropriate local and employer guidance. Further information is available in ***Appendix 2: Websites and further information.***

5. Making and maintaining agreements

Both client and psychologist benefit by having arrangements for the work clearly set out from the start. Psychologists should be aware that all professional engagements are ultimately governed by the law of contract. A legally enforceable contract can arise as a result of the parties' entering into a written agreement, but can also arise as a result of a verbal agreement between the contracting parties.

A contract arises if the following are present:

- one of the parties (the offeror) had made an offer to the other party (the offeree);
- the offeree accepts the offeror's offer;
- there is consideration (i.e. something of value) passing from each party to the other, e.g. the offeror provide services to the offeree; the offeree pays the offeror;
- the parties intended to create a legal binding arrangement; and
- the terms of the contract are sufficiently certain.

While this does not mean that all client engagements are made subject to an agreed contract document, it does mean that in the worst-case scenario of a complaint against a psychologist being made, it will be very helpful for the psychologist to be able to demonstrate that they have met their professional obligations to their client. This will be best done by demonstrating that an agreement was made by both parties who knew what they were agreeing to, that the parties had the legal capacity to make such an agreement and that what they were agreeing to is permitted under the law. Where the client does not have the capacity, best interest decisions need to be made in accordance with the Mental Capacity Act. Further information is available in ***Section 6: Obtaining informed consent***.

Psychologists may wish to include the following when making agreements:

- the role and function of the psychologist;
- the psychologist's relevant qualifications, areas of expertise and ways of working;
- relevant limitations of the psychologist's practice, e.g. assessments not accepted or types of activity not undertaken;
- where the psychologist is appointed to work with a third party, the psychologist should make clear their obligations to each of the clients concerned and each client's obligations under the agreement and ensure that there are no conflicts or ambiguities;
- the extent of the psychologist's power and responsibilities when acting on behalf of other agencies;
- obligations in relation to duty of care and safeguarding, and related limitations to confidentiality;
- how confidentiality of client information and data is assured and any limitations to that confidentiality;
- how conflicts of interest will be managed if applicable;
- the client's, or other party's, rights of access to stored information;
- the use of any one-way viewing screens or video or audio recording and the security of any recorded material;

- the nature of psychological activities involved, the reasons for undertaking them and information about the likely outcomes;
- the availability of the psychologist to the client;
- details of fees, together with application of VAT if non-clinical services, or expenses to be billed in connection with the work undertaken;
- what is expected from the client as their contribution to the engagement with the psychologist, expectations for payment and consequences of non-payment;
- ownership of intellectual property rights;
- what might cause a breach of the agreement;
- the rights of each party to withdraw from the agreement and the consequences to any financial agreement;
- recourse to dispute resolution or law;
- the equality and justice aspects of social policies and their possible impact;
- external ethical scrutiny and approval of the engagement, where appropriate; and
- arrangements to terminate the retainer.

In advance of any psychological assessment, the client should be made aware of the availability of services, and the existence of any waiting lists for intervention.

For some approaches, intervention follows an evolving path, unique to each client and his or her life circumstances, which cannot be precisely predicted in advance. Clients should be made aware of this uncertainty, and predictions should be made on the best judgments. It is recognised that it is sometimes unrealistic and undesirable to provide detailed information on all aspects of psychological intervention, and consent should be obtained to a general strategy rather than specific procedures. Further information is available in this document or the ***Society Website: http://beta.bps.org.uk/Practice-Guidelines.***

5.1 The practitioner's right to withdraw their service

There are circumstances in which a psychologist may decide to terminate the agreement for provision of psychological services. The circumstances may be personal or professional.

The personal circumstances may include but will not be restricted to leaving employment in a psychological service, incidences of illness or family commitments.

The professional issues may relate to service structural changes, safety, or provision of most appropriate service.

In these circumstances, psychologists will, as far as possible, work to ease the transition of service provision and give as much notice as is practical in the particular situation.

5.2 Referrals

Where a psychologist finds themselves unable to come to an agreement with a client, the psychologist may refer the client to a suitably qualified colleague. Psychologists will both make and receive referrals when working in services with other professionals.

In making referrals, psychologists should consider the needs of the client and to the best of their knowledge refer to another professional with the appropriate skills and experience.

In receiving referrals, the psychologist should consider whether the referral is appropriate for psychology, establish the client's understanding of the purpose of the referral, and consider as far as possible prior to meeting the client whether the referral falls appropriately within their own areas of practice.

5.3 Representation of the qualifications and status of the psychologist

HCPC registration and BPS Chartered Status

Psychologists are encouraged to state their registration with the HCPC and protected title(s). This will provide assurance that the psychologist meets national standards of training and professional skills.

Use of the 'consultant' title

The term 'consultant' generally does not have a formal definition. Within the medical field it is used by doctors who have considerable experience and proven expertise demonstrated through examination within their respective Royal Colleges.

While there is no clear comparable grading structure for psychologists outside the NHS (within the NHS, the consultant title is used by psychologists who are employed in Band 8C, 8D and 9 positions), the use of this title would be seen to reflect both seniority and specialist expertise.

There is a difference between a 'consultant' psychologist and a psychologist who provides consultations in their context of practice. The Society expects that psychologists should be honest and accurate in representing their professional affiliations and qualifications, including such matters as knowledge, skill, training, education and experience.

The Society's position is that this would be applicable in any situation where expert knowledge or skills is being marketed or promoted, whether or not this is for financial gain. Further information is available in ***Society Document: Guidance on the use of the title 'Consultant Psychologist'***.

6. Obtaining informed consent

Psychologists should always ensure that they have sought and received the consent of those they work with, given of their own free will, without undue influence.

The concept of informed consent relates to the client's right to choose whether to receive psychological services, and to make this choice on the basis of the best information available presented in the most appropriate way. The principles apply, whether the psychologist works in the public, private or voluntary sector or in independent practice.

Psychologists should obtain the informed consent of the client in an appropriate manner prior to undertaking any assessment, intervention or research activities. In all circumstances, common sense and ethical practice should apply when considering the approach to gaining informed consent from those with whom the psychologist is working.

This section refers, in the main, to consent with adults with capacity. Further information on informed consent with discrete communities where further consideration may be needed is available in ***Sections 6.1 to 6.4***.

Obtaining informed consent involves a process which is dynamic and is relevant to the specific assessment, intervention or decision being made at that time. When there are substantive changes in the intervention or when the psychologist has reason to consider the client may no longer consent, consent should be reviewed. Psychologists should ensure that their clients are enabled to play an active role in this process. Clients should be encouraged to ask questions whenever they are in doubt.

Psychologists should be aware that a client's desire for help, and the immediate impact of the psychologist's supportive listening, may affect the client's ability to make informed choices about the help they wish to receive. They should also be aware that their own desires to help a client may bias their presentation of information, such as the probability of successful outcomes.

Psychologists should be aware of the complexities of obtaining informed consent to treatment due to the perceived power, status and authority of the professional psychologist. It may not be clear if the consent given is freely given by the client or, for example, is part of a pattern of compliance towards authority figures. Equally, a client may say that they understand the explanation given by the psychologist, and accept a plan for intervention, in order to avoid the discomfort of being seen not to understand the psychologist's complex language and ideas.

Obtaining informed consent is particularly difficult when the client is obliged to undertake the psychological intervention as part of an employment process or performance measure where they may have obligations under their employment contract; or when detained.

There should ideally be an ongoing dialogue between client and psychologist, as part of the process of joint decision-making. At any point, the client should feel free to ask questions about the impact of the treatment and withdraw consent to continue.

Psychologists should attempt to intervene against the express wish of a client only after careful consideration and in line with relevant legislation, policies and professional practice.

Provision of information for informed consent

In order to ensure that the client has all the information necessary to make an informed decision about whether to take part or not in a psychological activity, they must be provided with relevant information, such as that listed below, in a format that is designed to meet their specific needs.

The psychologist should consider providing information about the following:

- what the psychological activity involves, as far as this is consistent with the model of interaction, e.g. there will be limits in the use of some non-directive therapies and psychometric assessments;
- the benefits of the activity, either directly to the client in the case of assessment or intervention, or indirectly in the case of systemic intervention, or to potential theoretical advances or service improvement;
- any alternative assessment or treatment options and their known availability;
- foreseeable risks and how minor or serious they may be, for example the potential to feel worse at stages during therapeutic interventions;
- what might be the benefits and potential costs and risks to them of engaging or not engaging in the proposed psychological activity; and
- the client's right to withdraw their consent from assessment, treatment or intervention at any stage, along with information about any likely consequences of such withdrawal.

Consent to involvement of others

Psychologists have an obligation to ensure that prospective clients are informed of the extent and limitations of confidentiality with respect to anticipated services, the purposes of any assessment, the nature of the procedures to be employed or the intended uses of any product such as notes or recordings, before the assessment or intervention starts. Further information is available in ***Section 7: Managing data and confidentiality.***

The psychologist should ask the prospective client: whom they would wish to be informed of their assessment or treatment, if anyone; and the information they are willing to share where communication is essential, for example to the referring agent or organisation, management or court. Wherever appropriate, including in the law, the client should have copies of reports or letters or be given feedback so that they are kept fully informed.

If it is deemed necessary to move from individual contact to include others this should where possible be done with the client's prior consent.

Psychologists may be asked to provide consultancy or advice to colleagues about an identified client, without that person's knowledge or when the client has indicated that they do not want to have direct contact with the psychologist. In these circumstances, the psychologist will need to consider their potential involvement and the need for consent.

A psychologist who draws upon the work of other professionals in preparing a report, should seek their consent, where possible and if not already in disclosed records, to include that material and should acknowledge its source in the report.

If a report is requested which draws upon previous or concurrent investigations of a client in other contexts, for example NHS records in the preparation of a report for the court, the client's consent or relevant authority's consent for that information to be used should be sought.

If psychologists wish to use reports on clients which have been compiled by other professionals, they should do so only with the consent of those professionals and use the reports only in the context for which the report was specifically provided.

Information on and consent to record-keeping

Express consent must be sought in advance for the use of video, audio recording or one-way screens, with a clear explanation of the purpose of these. Further information is available in ***Section 7.1: Information governance.***

6.1 Informed consent for court

When a psychologist is instructed to give evidence in court, it is the court that should be informed and whose authority should be sought for the work undertaken. When serving as a witness in the legal arena, the psychologist is responsible to the court, rather than to either party.

6.2 Informed consent with children and young people

All children and young people, whatever their age or status, have a right to express their views freely and be involved in any decision-making that affects their lives, which includes judicial and administrative proceedings[40]. Therefore, psychologists who seek to work with children or young people must gain their informed consent. This applies whether the child or young person or another agent with legitimate responsibility for the child or young person has made the request for involvement. Any direction or guidance provided by parents or other caregivers must be 'in accordance with the child's evolving capabilities' and support the 'exercise by the child of his or her rights'[41]. The onus is then on the adults to provide appropriate support to enable the child or young person to express their views and contribute to decision-making.

Every psychologist should consider how they can:

- provide an accessible explanation to the child or young person about their work as a psychologist;
- offer a clear reason for their possible involvement;
- provide an opportunity for the child or young person to talk about what working with the psychologist might involve.
- discuss and agree how information is recorded and possibly shared with others with an awareness that young people who are 'Gillick competent' can consent to information not being shared with parents;

- discuss how the child or young person will be kept safe;
- ensure that the child or young person has understood the psychologist's role and has given their informed consent;
- ensure the child or young person understands they can withdraw their consent at any point;
- ensure their practice acknowledges and respects the culture, community and context of the child or young person.

Occasionally, a disagreement over consent may arise between parent/carer and child or young person and/or between parents/carers. The psychologist would make every effort to resolve the difference of views, perhaps seeking, with agreement, involvement of an appropriate family member and/or a colleague, although as discussed above, a young person who is 'Gillick competent' can legitimately request that family members (including parents) are not involved or informed of any involvement. If the disagreement is not resolved, the psychologist should draw on their professional experience to act in the best interest of the child or young person seeking consultation and support through appropriate channels, including safeguarding and legal departments, and consultation with appropriate colleagues including other professionals.

6.3 Informed consent with people who may lack capacity

It is likely that psychologists at some stage within their careers will be working with people who lack capacity to consent to assessment or treatment. This could be because of a wide range of difficulties such as intellectual disability, brain injury, dementia, severe mental health difficulties, and neurological conditions. As a result, it will often be necessary to make a judgment about a client's ability to give informed consent. This should include whether the person is able to:

- understand the information relevant to the decision (e.g. psychological treatment);
- retain that information;
- use or weigh that information as part of the process of making the decision; and
- communicate their decision (whether by talking, using sign language or any other means.)

The Mental Capacity Act 2005 contains 5 key principles which it is important to understand:

1. A presumption of capacity;
2. Individuals being supported to make their own decisions;
3. Individuals have the right to make 'unwise' decisions;
4. Anything done on behalf of a person with a mental capacity issue should be in their best interests; and
5. An intervention should be on the basis of the 'less restrictive option' weighed up in the particular circumstances of the case.

The Mental Capacity Act Code of Practice[42] expands upon these points (and indeed all aspects of the Act), highlighting the need to assist a client in making a decision for

themselves (with the use, for example, of memory aids, simplified resources, etc.). It should also be noted that the fact that a person is able to retain the information relevant to a decision for a short period does not prevent them from being regarded as able to make the decision.

The Mental Capacity Act (2005) provides a clear framework for what to do if a person lacks capacity to make a range of decisions, including consenting to treatment. The principle of 'best interest' must be followed, and the Act states clearly who needs to be consulted in relation to making such a decision and ensuring that the individual's wishes are considered.

It is good practice to give full information (possibly using adapted resources) to clients even when they are not deemed able to give informed consent. The psychologist must, so far as reasonably practicable, permit and encourage the client to participate, or to improve their clients' ability to participate, as fully as possible in any act done for the client and in any decision affecting them.

In some circumstances, it is possible that there may be others who have been given legal authority for decision-making on behalf of others, such as Power of Attorney for Health and Welfare or Deputyships for Health and Welfare. It is important to note that patients might also have created Property and Affairs Lasting Powers of Attorney. Those acting under a Property and Affairs power alone will not have authority to make decisions in relation to a patient's treatment. If someone is a Health and Welfare Attorney or Deputy, those persons will be able to make those decisions on behalf of others. It is also necessary to ensure that the client has not made an Advance Decision to refuse treatment prior to the loss of capacity, although this is unusual in relation to psychological treatment.

In some clinical contexts, particularly relating to brain injury, intellectual disabilities and dementia, issues related to capacity and best interest are particularly prevalent. Psychologists practising in these areas need to ensure sufficient knowledge and expertise. Further information is available in ***Society Document: Guidance on determining the best interests of adults who lack the capacity to make a decision for themselves.***

6.4 Informed consent with people as employees

Tripartite arrangements where an employer commissions and pays for an assessment or intervention, such as diagnostic assessments for neurodiversity and cognitive functioning return to work assessments, or coaching, potentially give the employer access to data that they will struggle to interpret, or may misinterpret, for example test scores and details of personal life. It is important that the psychologist protects the employee by giving the employer only what they need to know and can reasonably require for the purpose of employment.

The Psychologist should consider whether they will be gathering information that is not usually held by an employer, or is not held routinely for all employees, for example IQ scores and childhood experiences. If so, the psychologist should consider abridging documentation so that the employer receives only the information they 'need to know',

and the employee can if necessary hold a full copy for future reference. This prevents discrimination against employees who are subject to in depth assessment for reasons related to illness, neurodiversity or disability from being unfairly compared to their peers. It also prevents complex psychological information from being held by those who are not qualified to interpret it.

Agreements should be made explicitly about the information which can be shared with the commissioning organisation. In order to aid transparency, information should normally be sent to the client prior to being shared with the organisation.

6.5 Informed consent with detained persons

Prisoners

Informed consent may be harder to obtain when a client is detained. Psychologists working with detained persons should be aware that, as well as UK law, the UK is signatory to a number of conventions on the treatment of detained persons. These conventions not only outlaw physical ill-treatment, but also certain kinds of psychological pressure. For example, it is contrary to the UN Convention on Torture to apply psychological pressure to elicit a confession, or compliance with a regime. In this context, 'psychological pressure' could include making progression contingent on compliance with a particular aspect of the regime. Practitioners should be particularly mindful of the power imbalance in forensic contexts, which is far more acute than is generally found in non-justice system based settings. Only offenders detained in secure hospitals can be required to comply with assessments or treatments under involuntary detention sections of the Mental Health Act.

Mental Health Detentions

For psychologists there can be potential conflicts of interest or what could be better termed 'competing duties of care' between the roles of Responsible Clinician (RC) (for further information on this role see Section 3.5) (including the duty to detain or otherwise compel participation in treatment) and that of psychologist (including, principally, the duty to establish freely-given consent wherever possible to enhance the efficacy of the therapeutic intervention). The MHA Code at chapter 24.34 (medical treatment) states that permission given by a patient to a particular treatment 'under any unfair or undue pressure' is not consent (p.257).

Good outcomes for psychological therapies are associated with positive therapeutic alliances and good working relationships between therapists and patients. The potential for even perceived abuse of power and the inherent power differential between an RC and a detained patient subject to the MHA runs a risk of rupturing this relationship or it becoming coercive. Psychologist RCs must therefore remain aware of and give full consideration to any potential competing duties of care between the RC and psychological therapist roles when providing psychological treatments to patients over whom they have compulsory powers.

The main issues to be considered by psychologist RCs when addressing potential competing duties of care in this context include the following:

1. Psychological treatments (with the possible exception of indirect interventions delivered by proxies such as paid staff and carers) are more likely to be effective when informed consent is obtained. As such, RCs acting as psychological therapists should utilise all reasonable and ethical attempts to obtain consent from patients before proceeding with psychological treatment. The *Code* at chapter 24.34–24.39 (p.257) provides guidance on obtaining consent.
2. The Act permits psychological treatment to be given without consent and the Code provides guidance on how to proceed with treatment in these circumstances (chapter 24.40–24.44, pp.257–258). There may be circumstances, especially when significant risks to others or self have been identified, when it is considered to be necessary for a psychologist RC to proceed with providing psychological treatment without consent. In such circumstances then there should be, where practicable, prior discussion with the MDT involved in the patient's treatment and care about the risks involved. Careful consideration should be given to the availability and merits of another suitably qualified member of the team providing the psychological treatment required with the RC remaining in overall charge of the client's care.
3. There may be situations where it is judged that informed consent cannot be clearly obtained, or where it would appear another available practitioner would be more likely to achieve a more effective outcome (perhaps due to the power differential between patient and RC). In such situations the psychologist RC is advised to refer on to other members of the treatment team who are able to provide the psychological treatment needed, while the RC remains in charge of overall care.

7. Managing data and confidentiality

7.1 Information governance

Psychologists should follow local and national guidance and statutory responsibilities regarding management of data. Psychologists should make, keep and disclose information in records only in accordance with national policy and legislation, and the policies and procedures of the organisation(s) they are employed by/working in collaboration with. Further information is available in ***Section 1.1: Legal and professional obligations of psychologists, Appendix 1: Relevant legislation*** and ***Appendix 2: Websites and further information.***

Psychologists must bear in mind the potential impact of the information in their records on all who may have access to such records, for example, the client, other professionals, managers, authorised carers, etc. Where possible, distinction should be made between fact, observation and opinion, and judgemental comments should be avoided. Psychologists are responsible for holding their records securely to ensure the confidentiality of the information contained within them and to control access to them. Further information is available in ***Society Guidance: Guidelines on the use of Electronic Health Records.***

This guidance applies to all record-keeping on clients, their relatives, carers and/or associates, and their organisations, regardless of the media in which information is held, e.g. written notes and reports, audio- and video-recordings, paper and electronic records, etc.

Records made, kept or accessed by psychologists should be:

- systematic and appropriately detailed;
- in clear language/format;
- accurate;
- up to date; and
- relevant to professional work and to the purpose for which they were collected.

Clients have a legal right to access records concerning them, and this right is enshrined in legislation. Additionally, it is good practice for clients to be given feedback on their content. Sharing records with clients supports the collaborative approach of psychologists and enables clients to have full and effective involvement. Client access to records will be restricted to information about themselves and not third parties. Restrictions will also apply when disclosure would place the clients or others at risk of serious harm.

In tripartite arrangements involving an employer access to information should be governed by agreements made explicitly about the information which can be shared with the commissioning organisation.

Shared records

In some organisations in which psychologists work single, multi-professional, client-based records are held. Such records are designed as shared documents (paper or electronic),

the function of which is primarily to facilitate inter-professional communication to ensure the safe and effective delivery of high quality services. Such records may be shared among organisations/agencies to facilitate care and/or exceptionally, to safeguard the client or others, including the general public. In some contexts, clients have the right to object to their data being disclosed to a third party even someone who might provide essential healthcare. Psychologists should be aware of local codes and policies. Further information is available in ***Section 3.5: Working with other professionals***, ***Section 7: Managing data and confidentiality*** and ***Appendix 2: Websites and further information.***

Psychologists should include in the shared record all information about their work with clients and related others which is required to ensure appropriate multi-professional care and to safeguard the client and relevant others, including the general public.

Third-party and sensitive material should be clearly marked. There should be clarity/clear communication within the multi-professional team about what is and is not shared with the client if there are safeguarding concerns. A system needs to be established about how suspicions and causes of concern are recorded and/or shared.

Where shared records are held, other professionals involved with the clients will have access to such records. This should be explained to the clients at the onset of engagement with them.

The use of sealed envelopes is no longer considered good practice following the findings from serious untoward incident investigations where the existence of sealed envelopes compromised care.

Assessment materials

Psychologists should be mindful at all times of the confidential nature of assessment materials. Many assessment measures are invalidated by prior knowledge of their specific content and objectives. Psychologists who use these materials are required to respect their confidentiality and to avoid their release into the public domain (unless this is explicitly allowed in the nature of the instrument and by the test publisher). Psychologists should, therefore, take reasonable steps to prevent misuse of test data and materials by others. Further information is available from ***Appendix 2: Websites and further information.***

In many organisations, there is only one shared records system. In these cases, it is necessary for psychologists to be able to use the shared records system to hold raw data from psychometric assessment. The results of psychometric assessment will be incorporated into reports which explain their context and appropriate interpretation, and which are included in the shared institutional record. In relation to the visibility of the psychometric instrument and the raw data to other members of the multidisciplinary team who are not psychologists, the onus is on the other professionals not to interpret information where they are unqualified to do so, just as the psychologist would not interpret, for example, physical healthcare test results they are unqualified to interpret. Psychologists may consider whether it is appropriate to mark assessment materials so their nature is clear.

Additional data

Psychologists may wish to keep separate notes to aid their work but which are not intended for sharing with others or to be part of the permanent client record. These notes, often called process notes, which are written for the purposes of reflection on practice, should be anonymised with no other identifying links e.g. initials, appointment time, so that these notes therefore are clearly not part of the client record. Process notes may, for example, be used for reflection and supervision. If process notes are made to assist in compilation of a report, the material should be incorporated, as relevant, into the final report and the process notes then destroyed.

Long-term illness, incapacity or death of a psychologist

Most organisations will have procedures in place in the event of illness, incapacity or death of a psychologist. Psychologists in independent practice are advised to make a professional will and to appoint a professional executor, probably an experienced colleague, whose role it would be to take charge of client records, to inform the clients involved and, where appropriate and practicable, to make provision for continuity of the service provided.

Retention and destruction of records

Psychologists' records should be held securely for as long as they are required for the purpose of psychological work. Psychologists must follow legal requirements, national and local policy frameworks and procedures regarding the retention or disposal of records after the psychologist's work is concluded. Psychologists should ensure that they keep up to date with requirements.

For independent practitioners general guidance is that many independent psychologists keep records relating to contact with adults for 7 years, and follow NHS guidance in relation to children. Where the records derive from work undertaken within an organisation, the maintenance of these records is determined by the organisation's policies and legal requirements.

Retention and destruction of health records, both paper and electronic, is covered in the NHS code of practice for records management. Generally speaking, retention is until age 26 for people seen as children; 20 years after the last contact for adults, and 8 years after death if the death occurred while the person was in the care of the NHS. There are specific requirements for mental health services depending on the nature of the contact.

In education settings, Local authorities generally retain Education Health and Care Plans for 35 years after the case has been closed. Other records are retained until the child is 25.

All records must be destroyed under confidential conditions following organisational procedures or for independent practitioners using a destruction service or process which meets industry standards for document management and can provide the appropriate certification.

7.2 Confidentiality

Clients are entitled to expect that the information they give to psychologists about themselves and others will remain confidential. Psychologists have a duty not to disclose

such information except as discussed below and to bring their confidentiality practice to the attention of their clients, employers, managers and any other professionals involved.

Psychologists have a duty to inform involved parties of their confidentiality standards and practice at the point of first contact. Clients should be informed of the limits of confidentiality where information about them may be shared and confidentiality breached, for example for reasons of safeguarding, requirements of the law, and public protection.

Psychologists have a duty to be aware of the content of any other relevant guidelines and of any other policy guidelines which set out local expectations.

Use of client data for audit must follow the Caldicott principles, which, designed for the NHS, provide helpful guidance for any setting in terms of when it is appropriate to use with client-identifiable data and when anonymised data should be used[43]. Generally under data protection legislation, it is necessary to obtain specific informed consent for the use of client data for particular purposes, and to inform clients of the purposes for which their data is being collected and how it will be used. Further information is available in ***Appendix 2: Websites and further information.***

Disclosure of information

If disclosure of information is deemed necessary, psychologists should obtain specific informed consent from their clients, making the consequences of disclosure as clear and unbiased as possible. There are a number of circumstances where this might not be possible or may not apply: for example where the health, safety, security or welfare of the client or someone else may otherwise be put at risk; and if there are legal or safeguarding responsibilities, such as the need to avoid 'tipping off'. If confidentiality is broken without consent, the client should be told what has been said and to whom, unless such disclosure may expose the client or others to serious harm or is contrary to legal or safeguarding obligations.

Psychologists who are faced with the difficult decision as to whether to disclose information without a client's consent must weigh carefully the arguments for and against disclosure. The responsibility for this decision lies with the individual psychologist although they may seek advice and guidance from appropriate sources such as their employing organisation's Information Governance or Data Protection Lead, Clinical Governance Lead, Caldicott Guardian, Safeguarding named and designated professionals, or legal departments. These other professionals can be the most helpful sources of advice in difficult disclosure situations. Independent practitioners may wish to consult the legal helpline of their professional indemnity insurer.

Circumstances may emerge where clients may present a risk to others or to themselves, or be at risk from others whom they wish to protect. It is then necessary to discuss the importance of disclosure and to encourage it, for example to partners of HIV positive clients, and to employers if a client's mental health status presents a risk to others via driving, handling machinery or interaction in a working situation, for example, flight deck crew. Disclosure without consent, or against the client's expressed wish may be necessary in situations in which failure to disclose appropriate information would expose the client, or

someone else, to a risk of serious harm (including physical or sexual abuse) or death.

The psychologist must weigh up the needs and interests of their own client against the wider welfare, protection and safeguarding of the public.

Disclosure to clients' employers, insurance companies and others

Psychologists have a duty to ensure, at first contact, that clients understand the purpose of any assessment undertaken at the request of employers, the DVLA or insurance companies, and of the psychologist's obligation to disclose the results of that assessment. In the case of assessment for fitness to work or to drive, they should obtain the client's written consent.

Psychologists should consider what each party involved needs to know, gaining understanding and agreement on which aspects will be fed back, in advance. For example, the full detailed and raw scores obtained by a psychologist in recruitment assessment processes may be unsuitable for an employer to receive in full. The commissioning body should be made aware of the decision-making data that they originally requested, in the case of an employer this could include strengths and weaknesses, and recommendations for employer actions, for example.

Primary clients should be advised about and able to preview, with opportunity to ask questions first, any data that will be sent to an employer about them. Bear in mind that the informed consent difficulties still stand and that an employee or potential employee can withdraw consent for the employer to be informed of any part of their results.

This can be very difficult to manage in practice, and requires psychologists to make these agreements with their commissioners before they start the work, so that all are informed of the risks in the service delivery. Further information is available in ***Section 3.4: Working with multiple clients.***

Disclosure after a client's death

After a client's death, relatives or other authorities may seek access to the psychologist's records. In the first instance, the psychologist is advised to follow organisational procedures where they exist which usually deal with the administrative proofs required such as proof of death, proof of kinship and right to access the material requested.

A psychologist's duty of confidentiality continues after a client has died. The psychologist will need to weigh up the circumstances around the request for disclosure and what personal information is being sought. If there has been a specific request by the client for their information to remain confidential, their wishes should usually be respected. If the psychologist is unaware of any instructions from the client, when considering requests for information the following should be taken into account:

- the purpose of the disclosure;
- whether the disclosure of information is likely to cause distress to, or be of benefit to, the client's partner or families;
- the permission of a surviving relative or next of kin is not required, and does not authorise disclosure of confidential information, although the views of those who were close to the client may help the psychologist decide if disclosure is appropriate;

- whether the disclosure will also disclose information about the client's family or anyone else; and
- whether the information is already public knowledge or can be anonymised or coded.

There may be circumstances where the disclosure of information is required, for example:

- to support an inquest or fatal accident inquiry;
- where the disclosure is required by law, is authorised under section 251 of the NHS Act 2006, or is justified in the public interest, such as for education or research;
- in the case of national confidential inquiries or for local clinical audit; and
- when a person has a right of access to records under the Access to Health Records Act 1990 or Access to Health Records (Northern Ireland) Order 1993.

7.3 Confidentiality when safeguarding

In exceptional circumstances it may be necessary to breach the client's confidentiality with or without their immediate knowledge or consent. This would be the case where there are significant risks to the client's psychological wellbeing; where the alleged perpetrator may be a current risk to others or where there is risk of jeopardising a potential investigation. Any decision to breach confidentiality cannot be taken lightly, but can be justified and accounted for if made in good faith because of safeguarding concerns. This is supported by professional guidance. The focus of any intervention including any breach of confidentiality must be on promoting a proportionate, measured approach to balancing the risk of harm with respecting the client's capacity to consent, their choices and preferred outcome for their own life circumstances.

Specified authorities may need to share personal information to ensure, for example, that a person at risk of radicalisation is given appropriate support. When considering sharing personal information, the specified authority should take account of the following:

- necessity and proportionality: personal information should be shared only where it is strictly necessary to the intended outcome and proportionate to it. Key to determining the necessity and proportionality of sharing information will be the professional judgement of the risks to an individual or the public;
- consent: wherever possible the consent of the person concerned should be obtained before sharing any information about them;
- power to share: the sharing of data by public sector bodies requires the existence of the power to do so, in addition to satisfying the requirements of the Data Protection Act 1998 and the Human Rights Act 1998; and
- Data Protection Act and the Common Law Duty of Confidentiality: in engaging with non-public bodies, the specified authority should ensure that they are aware of their own responsibilities under the Data Protection Act and any confidentiality obligations that exist.

In relation to health sector staff, government guidance states it is important that staff understand how to balance client confidentiality with the duty to report. They should also be made aware of the information-sharing agreements in place for sharing information with other sectors, and get advice and support on confidentiality issues when responding

to potential evidence that someone is being drawn into terrorism, either during informal contact or consultation and treatment.

7.4 Confidentiality for the court

Psychologists acting as expert or professional witnesses have a duty to disclose all of the evidence used to reach their opinion where directed by the court to do so.

This could include:

- the details of any tests and assessments administered with professional colleagues;
- notes made during report writing; and
- referenced academic articles or studies.

No information relating to an assessment or report should be disclosed outside the relevant proceedings without agreement. Psychologists should normally seek permission from the instructing party to disclose any information to another health care professional.

Where instructed directly by the court, the Crown Prosecution Service, Procurator Fiscal or a solicitor, the psychologist is required to report or comment on any or all aspects of the case that appear to the psychologist, as an expert in the field, to be relevant or pertinent. In such circumstances, the psychologist is not in a position to offer confidentiality to any person, and should make this position clear to any party with whom they have contact during psychological investigations or assessment.

In these circumstances, it will be important that the psychologist makes sure they are up to date with the legislation and policy guidance regarding public and media access to information available to whichever court or tribunal their instruction arises from. The psychologist will need this awareness so that they can explain to the adult or child concerned what the limits of privacy are in these legal circumstances. They will need to make clear to the client which information needs to be made accessible, by whom and under what circumstances. Only when the client understands this, can they give informed consent.

There are different levels of access to sensitive information in different legal contexts; this will include testimony, documents and professional and expert reports. Many proceedings typically take place in open court, to which the public has access. In these cases, there is a presumption in favour of providing information and documents to third parties which were relied upon by the court in reaching its decision, though not the entire court file.

Where court papers and other materials are received in electronic format, psychologists should ensure that these are stored in a secure, password-protected format. This may require the addition of additional security for documents that arrive in an unsecured form. Where psychologists submit reports in an electronic format they should ensure that these are in a secure, password-protected format.

Psychologists working with clients who are the subject of court proceedings may need to be careful to ensure that they keep all records which may be of relevance to the court process until it is clear that the court has reached a final conclusion, including any appeal that may have been heard.

With few exceptions, applications in the family court are heard in private, with only those immediately involved being allowed to attend and access information. It is possible, however, for duly accredited members of the media to attend hearings in the family court, subject to the power to exclude them on specified grounds.

In most family court proceedings, media representatives have no entitlement to receive or peruse court documents referred to in the course of evidence, submissions or judgment. If media representatives wish to see documents referred to in the family court they may apply to the judge for disclosure but they are subject to strict guidance in terms of what information they can divulge into the public domain.

7.5 Confidentiality with children and young people

When beginning direct work with a child or young person, the psychologist should discuss and agree who will have access to the information arising from the work, with direct reference to principles of 'Gillick competence'. In undertaking this discussion it is helpful to acknowledge that there may be those adults (e.g. parents/carers, other relevant professionals such as teachers, social workers, counsellors) who may have a supportive interest in the work and may wish to have appropriate access to information but the wishes of a 'Gillick competent' young person should take precedence unless there are safeguarding concerns.

Parents or those with legal responsibility may be made aware of this agreement if appropriate, although a young person deemed to be Gillick competent is able to agree to work with a psychologist independently. Those with parental responsibility do not have an automatic right of access to the psychologist's records by making a subject access request under data protection legislation.

The nature and purposes of any work will vary and this will determine how and to whom information will be shared, however the child or young person should always be made aware of who will have access to what and for what purpose and due consideration given to the wishes of a 'Gillick competent' young person about who can have access to information about any involvement with a psychologist. The child or young person should be fully aware of the content of any shared information, including as appropriate, copies of the documents. Whatever is agreed about information sharing including work where information is confidential, the psychologist must ensure the child or young person knows and understands that if there is a risk of harm the psychologist must follow safeguarding procedures.

7.6 Confidentiality with detained persons

When detained persons give informed consent to the collection of information, they do so for a specific purpose and for use by specific people. The use of such information for a different purpose or for use by different people would require separate consent. Thus, although a psychologist may interview and write a report on a detained person, consent for that purpose cannot be taken as allowing a third party access to the psychologist's records on that person, such as notes on (or recordings of) the interview. If psychologists are

put under pressure to reveal such information, they should seek the advice of colleagues including for example those responsible for governance or data protection. They should bear in mind that they have a legal duty to be aware of and comply with data protection legislation and professional confidentiality rules.

7.7 Confidentiality obligations during training

During training, no academic/training documents should identify clients to whom they relate (even by means for example of initials, service name or date of appointment) as any such potential identifiers could be used to trace the client and therefore make the document a part of the clinical record and subject to the relevant provisions of data protection legislation. This includes published reports, case studies prepared for trainee assessments and any articles or publications. Tutors and supervisors should communicate this to their trainees. Trainees should be clearly instructed to both make and keep separately those records which are part of the provision of psychological service and which belong to the service organisation and are subject to its policies and procedures; and papers which are anonymised and are part of the trainee's academic learning, and belong to the trainee and are subject to the training provider's policies and procedures.

Express consent should be obtained by trainees before audio- or video-recording their interactions with clients. If the client is unable to give informed consent, it is unlikely to be appropriate for the recording to be made. Careful consideration should be given before any material is recorded if the client is party to any legal proceedings or family or employment disputes. If material is to be used for purposes other than client care (including teaching and research), the client should be informed of the purposes of the recording. It should be made clear to clients how the material will be used and to whom it will be disclosed, for example, trainee students, other researchers, and supervisors.

The trainee and the client should come to an agreement about how long recorded material should be kept. The general principle is that recordings will be kept for as long as needed to fulfil the purpose for which the client has given consent and no longer. The security of the material must be maintained, and it must be destroyed at the agreed time limit if no longer required.

Informed consent is required before client material in an identifiable format may be published in case studies, presentations or other research reports. It is becoming common practice for clinical material in professional doctorate portfolios to be stripped out before the thesis is placed in online institutional repositories.

8. How to respond when things go wrong

8.1 Managing conflict with a client

Conflict with a client suggests that someone's expectations are not being met. The first objective should be to restore agreement or agree to make changes. The well prepared psychologist will have a client agreement in place and will be able to review the experience against the agreement with the client to address this question. Further information is available in ***Section 5: Making and maintaining agreements***. Even in the absence of an agreement, the psychologist would be advised to enquire with the client where their expectations are unmet or raise their own unmet expectations with the client. This can be an opportunity to put a belated agreement in place.

It may be that the parties agree to set aside the agreement and bring it to an early close. Agreeing to disagree may be a better outcome for psychologist and client who cannot restore agreement. Take account of any need for onward referral either within the service or elsewhere or back to the original referrer, and depending on the nature of the work setting, any financial obligations in closing the work.

The psychologist may find it helpful to consult with appropriate colleagues in preparation for the conversations with the client, such as line or service managers, those with other relevant organisational responsibilities, and supervisors. There may be more general lessons to be drawn as part of reflective practice in relation to the quality of the client agreement for future use.

8.2 Transparency and duty of candour

The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 duty of candour (regulation 20) requires all health and adult social care providers registered with the Care Quality Commission to be open with people when things go wrong. Psychologists need to be aware of the terminology relating to this regulation including:

- openness – enabling concerns and complaints to be raised freely without fear and questions asked to be answered;
- transparency – allowing information about the truth about performance and outcomes to be shared with staff, patients, the public and regulators; and
- candour – any patient harmed by the provision of a healthcare service is informed of the fact and an appropriate remedy offered, regardless of whether a complaint has been made or a question asked about it.

Psychologists also have a responsibility to ensure that they engage in open and transparent communications with people who use services and other 'relevant persons' (people acting lawfully on their behalf) in relation to care and treatment. Guidance from the Care Quality Commission on duty of candour outlines the specific requirements that providers must follow when things go wrong with care and treatment, including informing people about

the incident, providing reasonable support, providing truthful information, and making an apology. Psychologists are instrumental in supporting organisations to promote a culture that encourages candour, openness and honesty at all levels. Further information is available in ***Appendix 2: Websites and further information.***

8.3 Managing conflict in team settings

Dealing with breakdowns in working relationships, professional disagreements and fitness to practise concerns

As far as possible, psychologists should seek to resolve any conflict with or between other professional colleagues (including relating to consultation/supervision or line management) by clear communication, relevant evidence and collaboratively working through the issues in reasoned argument within the context of respectful relationships.

The psychologist should first approach the colleague in confidence, if it is appropriate, with relevant information, in a manner that is collegiate and helpful. If misgivings continue, the psychologist should consult with an appropriate colleague to share concerns and to seek advice. Where appropriate they should keep a written record of the meetings and steps taken to resolve any difficulties.

Where there is serious or continual disagreement, both parties need to take whatever action is appropriate in their professional context, consulting other experienced professionals as necessary.

Supervisors and line managers have professional obligations concerning professional standards, ethical practice and 'fitness to practise' issues. If line managers or supervisors have any concerns regarding performance in these areas, they have a duty to discuss these with the psychologist and, if necessary, address the matters by in the first instance following appropriate employment policies and procedures, or in the case of an independent practitioner, making a report to the HCPC.

Working in multi-professional or multi-agency contexts

Psychologists may find themselves in conflict with the approaches to work taken by other individual colleagues or by the multi-professional team or agency.

Psychologists should bring to the awareness of the multi-professional team or agency any difficulty in the group working together which may impact on the psychologist's ability to function effectively and ethically in their role. Such issues are best addressed when guided by national and local policy and current legislation before proceeding with multi-professional/multi-agency collaboration. Further information is available in ***Appendix 1: Relevant legislation.***

The psychologist may also have cause for concern about the ability of the team to provide for the needs of the client owing to interpersonal difficulties between members of the multi-agency or multidisciplinary team that might have an indirect impact on the client. As far as possible, psychologists should seek to resolve any conflict with or between other professional colleagues by clear communication, relevant evidence and collaboratively

working through the issues in reasoned argument within the context of respectful relationships.

If the situation remains unresolved for any reason, for example because it is judged not to be an issue for active management, the psychologist must make a judgement about whether their involvement in the team is helpful to the client or the working of the team. If not, the psychologist should consult with an appropriate colleague about whether they should disengage from that team.

A psychologist may also experience concerns about the competence or ethical practice of individual colleagues involved in joint working. These concerns may relate to the competence of the colleague to carry out a particular intervention, the appropriateness of an intervention for a particular client or problem, the nature of the relationship between a colleague and his or her client (e.g. potential abuses of power).

The psychologist should first approach the colleague in confidence, if it is appropriate, with relevant information, in a manner that is collegiate and helpful. If misgivings continue, the psychologist should consult with an appropriate colleague to share concerns and to seek advice. Where appropriate they should keep a written record of the meetings and steps taken to resolve any difficulties.

If they conclude that misconduct has occurred, psychologists should bring the matter to the attention of those charged with the responsibility to investigate such concerns, generally in the first instance an employer or in the case of an independent practitioner, the HCPC. Further information is available in ***Section 2.1: Working environment.***

8.4 Supporting a colleague when a complaint has been made

The receipt of a complaint or allegation can be distressing for all concerned, not least for the person who is the subject of the complaint or allegation. It is important that they receive advice and support from appropriate persons. Any potential conflicts of interest should be considered. It may be that a psychologist is not best placed to offer support and guidance as they may be called as a witness in the complaints process. Encourage colleagues to seek advice from an experienced colleague or supervisor where appropriate.

The psychologist should also be encouraged to seek the support of an accredited workplace trade-union representative who is skilled at supporting people in these situations and can access legal advice if necessary. Legal advice can also be obtained from the professional indemnity insurance broker, and sometimes from household insurance policies where the householder has taken out the legal advice additional option.

Complaints are an increasingly normal occurrence and must be handled in a professional manner. The complaint investigator or professional body will need the psychologist's version of events and any evidence before any conclusions are reached. Psychologists should support colleagues to respond promptly, objectively, factually and honestly to the complaint. The content of the complaint should always be held in confidence.

8.5 If the client remains unhappy

If any conflict or issue as referred to in this section cannot be resolved, it may be appropriate to advise a client or other individual that that they have a right to raise any concerns about a psychologist with the Health and Care Professions Council, further details of which can be found at www.hcpc-uk.org

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Appendix 1 – Relevant legislation

Unless otherwise stated, Acts can be found on the government website http://www.legislation.gov.uk/

United Kingdom and England

Care Act 2014

An Act to make provision to reform the law relating to care and support for adults and the law relating to support for carers; to make provision about safeguarding adults from abuse or neglect; to make provision about care standards; to establish and make provision about Health Education England; to establish and make provision about the Health Research Authority; to make provision about integrating care and support with health services; and for connected purposes.

Care Standards Act 2000

An Act to establish a National Care Standards Commission; to make provision for the registration and regulation of children's homes, independent hospitals, independent clinics, care homes, residential family centres, independent medical agencies, domiciliary care agencies, fostering agencies, nurses agencies and voluntary adoption agencies; to make provision for the regulation and inspection of local authority fostering and adoption services; to make provision for the registration, regulation and training of those providing child minding or day care' to make provision for the protection of children and vulnerable adults; to amend the law about children looked after in schools and colleges.

Children Act 1989

An Act to reform the law relating to children; to provide for local authority services for children in need and others; to amend the law with respect to children's homes, community homes, voluntary homes and voluntary organisations; to make provision with respect to fostering, child minding and day care for young children and adoption; and for connected purposes.

Children and Families Act 2014

An Act to make provision about children, families, and people with special educational needs or disabilities; to make provision about the right to request flexible working; and for connected purposes.

Data Protection Act 1998

An Act to make new provision for the regulation of the processing of information relating to individuals, including the obtaining, holding, use or disclosure of such information. The Act states that anyone who processes personal information must comply with eight principles, which make sure that personal information is:

- fairly and lawfully processed;

- processed for limited purposes;
- adequate, relevant and not excessive;
- accurate and up to date;
- not kept for longer than is necessary;
- processed in line with your rights;
- secure; and
- not transferred to other countries without adequate protection.

Equality Act 2010

An Act to make provision to require Ministers of the Crown and others when making strategic decisions about the exercise of their functions to have regard to the desirability of reducing socio-economic inequalities; to reform and harmonise equality law and restate the greater part of the enactments relating to discrimination and harassment related to certain personal characteristics; to enable certain employers to be required to publish information about the differences in pay between male and female employees; to prohibit victimisation in certain circumstances; to require the exercise of certain functions to be with regard to the need to eliminate discrimination and other prohibited conduct; to enable duties to be imposed in relation to the exercise of public procurement functions; to increase equality of opportunity; to amend the law relating to rights and responsibilities in family relationships; and for connected purposes.

Health and Social Care Act 2012

An Act to establish and make provision about a National Health Service Commissioning Board and clinical commissioning groups and to make other provision about the National Health Service in England; to make provision about public health in the United Kingdom; to make provision about regulating health and adult social care services; to make provision about regulating health and social care workers; to make provision about public involvement in health and social care matters, scrutiny of health matters by local authorities and co-operation of health care services; to make other provision about information relating to health or social care to make other provision about health care; and for connected purposes.

Mental Capacity Act 2005

An Act to make new provision relating to persons who lack capacity; to establish a superior court of record called the Court of Protection in place of the office of the Supreme Court called by that name; to make provision in connection with the Convention on the International Protection of Adults signed at the Hague on 13th January 2000; and for connected purposes.

Mental Health Act 1983 as amended 2007

An Act to consolidate the law relating to mentally disordered persons. The main purpose of the Mental Health Act 1983 as amended 2007 (MHA) is to allow compulsory action to be taken, where necessary, to ensure that people with mental disorders receive the care and treatment they require for their own health or safety, or for the protection of other people.

Offender Rehabilitation Act 2014

An Act to make provision about the release, and supervision after release, of offenders; to make provision about the extension period for extended sentence prisoners; to make provision about community orders and suspended sentence orders; and for connected purposes.

Official Secrets Act 1989

An Act to replace section 2 of the Official Secrets Act 1911 by provisions protecting more limited classes of official information.

Regulation of Investigatory Powers Act (RIPA) 2000/Investigatory Powers Act 2016

An Act to make provision for and about the interception of communications, the acquisitions and disclosure of data relating to communications, the carrying out of surveillance, the use of human intelligence sources and acquisitions of the means by which electronic data protected by encryption or passwords may be decrypted or accessed; equipment interference, bulk personal datasets and other information; to make provision about the treatment of material held as a result of such interception, equipment interference or acquisition or retention; to establish the Investigatory Powers Commissioner and other Judicial Commissioners and make provision about them and other oversight arrangements; to make further provision about investigatory powers and national security; to amend sections 3 and 5 of the Intelligence Services Act 1994.

Safeguarding Vulnerable Groups Act 2006

An Act to make provision in connection with the protection of children and vulnerable adults. Safeguarding means protecting people's health, wellbeing and human rights, and enabling them to live free from harm, abuse and neglect.

Northern Ireland

Children Act 1989 – NI has a Criminal Justice Children's Order 1998

An Act to reform the law relating to children; to provide for local authority services for children in need and others; to amend the law with respect to children's homes, community homes, voluntary homes and voluntary organisations; to make provision with respect to fostering, child minding and day care for young children and adoption; and for connected purposes.

Criminal Justice (Northern Ireland) Act 2013

An Act to amend the law relating to sex offender notification, sexual offences prevention orders and human trafficking; to provide for the destruction, retention, use and other regulation of certain fingerprints and DNA samples and profiles; to provide for the release on license of persons detained under Article 45(2) of the Criminal Justice (Children) (Northern Ireland) Order 1998.

Criminal Justice (Northern Ireland) Order 2008 and Public Protection Arrangements in Northern Ireland (PPANI)

The Criminal Justice (NI) Order 2008 introduced a new sentencing framework, including extended and indeterminate sentences for public protection to reduce the risk of dangerous sexual and violent offenders being released into the community until the risk they pose is considered by the parole commissioners to be at a manageable level. The Public Protection Arrangements in Northern Ireland (PPANI) contained within the Criminal Justice (NI) Order 2008, place a duty on a number of agencies, within the criminal justice sector and elsewhere, to cooperate in the interest of better assessment and management of risk posed by serious sexual and violent offenders.

Justice Act (Northern Ireland) 2015

An Act to provide for a single jurisdiction for county courts and magistrates' courts; to amend the law on committal for trial; to provide for prosecutorial fines; to make provision in relation to victims and witnesses in criminal proceedings and investigations; to amend the law on criminal records and live links; to provide for violent offences prevention orders; to make other amendments relating to the administration of civil and criminal justice; and for connected purposes.

Mental Capacity Act (Northern Ireland) 2016

This Act fused mental health and mental capacity law into a single piece of legislation. The Act provides a framework for broader decision-making which includes: a statutory presumption of capacity, a requirement to support decision-making, mechanisms to allow individuals to plan for times that they do not have capacity, and safeguards to protect the rights of individuals when compulsory interventions or substitute decisions are required. It will remove the ability for someone to be treated for a mental health condition against his or her wishes if he or she retains the capacity to refuse such treatment, thus putting it on a par with the rights that individuals currently enjoy to make decisions regarding physical health treatment.

The Parole Commissioners' Rules (Northern Ireland) 2009

The Parole Commissioners for Northern Ireland are an independent body responsible for making decisions on the release and recall of prisoners sentenced to life, indeterminate custodial sentences, and extended custodial sentences, as well as the recall of prisoners serving determinate sentences.

The Sexual Offences (Northern Ireland) Order 2008

The Sexual Offences (Northern Ireland) Order 2008 lowered the age of sexual consent from 17 to 16 and incorporated significant changes to the law in relation to sexual offences in Northern Ireland; better protection for young people and people with a mental disorder from sexual abuse and exploitation; and sought to clarify issues surrounding consent in sexual assault cases and rape.

Scotland

Adoption and Children (Scotland) Act 2007

An Act of the Scottish Parliament to restate and amend the law relating to adoption; to make other provision in relation to the care of children; to enable provision to be made in relation to allowances in respect of certain children; and for connected purposes.

Adults with Incapacity (Scotland) Act 2000

An Act of the Scottish Parliament to make provision as to the property, financial affairs and personal welfare of adults who are incapable by reason of mental disorder or inability to communicate; and for connected purposes.

Adult Support and Protection (Scotland) Act 2007

An Act of the Scottish Parliament to make provision for the purposes of protecting adults from harm; to require the establishment of committees with functions relating to the safeguarding of adults who are at risk of harm; to amend the law relating to incapable adults; to allow the Public Guardian to intervene in court proceedings; to amend the law relating to mentally disordered persons; and for connected purposes

Children (Scotland) Act 1995

An Act to reform the law of Scotland relating to children, to the adoption of children and to young persons who as children have been looked after by a local authority; to make new provision as respects the relationship between parent and child and guardian and child in the law of Scotland; to make provision as respects residential establishments for children and certain other residential establishments; and for connected purposes.

Children and Young People (Scotland) Act 2014

An Act of the Scottish Parliament to make provision about the rights of children and young people; to make provision about investigations by the Commissioner for Children and Young People in Scotland; to make provision for and about the provision of services and support for or in relation to children and young people; to make provision for an adoption register; to make provision about children's hearings, detention in secure accommodation and consultation on certain proposals in relation to schools; and for connected purposes.

Mental Health (Scotland) Act 2015

An Act of the Scottish Parliament to amend the Mental Health (Care and Treatment) (Scotland) Act 2003 in various respects; to make provision about mental health disposals in criminal cases; to make provision as to the rights of victims of crime committed by mentally-disordered persons; and for connected purposes.

Mental Health (Care and Treatment) (Scotland) Act 2003

An Act of the Scottish Parliament to restate and amend the law relating to mentally disordered persons; and for connected purposes.

Protection from Abuse (Scotland) Act 2001

An Act of the Scottish Parliament to enable a power of arrest to be attached to interdicts

granted to protect individuals from abuse; to regulate the consequences of such attachment; and for connected purposes.

Protection of Children and Prevention of Sexual Offences (Scotland) Act 2005

An Act of the Scottish Parliament to make it an offence to meet a child following certain preliminary contact and to make other provision for the purposes of protecting children from harm of a sexual nature, including provision for implementing in part Council Framework Decision 2004/68/JHA; and to make further provision about the prevention of sexual offences.

Protection of Vulnerable Groups (Scotland) Act 2007

An Act of the Scottish Parliament to bar certain individuals from working with children or certain adults; to require the Scottish Ministers to keep lists of those individuals; to make further provision in relation to those lists; to establish a scheme under which information about individuals working or seeking to work with children or certain adults is collated and disclosed; to amend Part 5 of the Police Act 1997; to amend the meaning of school care accommodation service in the Regulation of Care (Scotland) Act 2001; and for connected purposes

Public Bodies (Joint Working) (Scotland) Act 2014

An Act of the Scottish Parliament to make provision in relation to the carrying out of functions of local authorities and Health Boards; to make further provision about certain functions of public bodies; to make further provision in relation to certain functions under the National Health Service (Scotland) Act 1978; and for connected purposes.

Regulation of Care (Scotland) Act 2001

An Act of the Scottish Parliament to establish the Scottish Commission for the Regulation of Care and the Scottish Social Services Council; to make provision for the registration and regulation of care services and for the registration, regulation and training of social service workers; to enable local authorities to provide and maintain residential accommodation in which nursing is provided; to make further provision as respects persons who have been looked after by local authorities; to amend the definition of 'place of safety' in the Children (Scotland) Act 1995.

Smoking, Health and Social Care (Scotland) Act 2005

To amend the Regulation of Care (Scotland) Act 2001 as respects what constitutes an independent health care service, the implementation of certain decisions by the Scottish Commission for the Regulation of Care or the Scottish Social Services Council, the provision of information to the Council and the minimum frequency of inspection of care services by the Commission to amend the Adults with Incapacity (Scotland) Act 2000 as respects authorisation of medical treatment; to amend the Public Health (Scotland) Act 1897 to introduce a right of appeal in certain cases under that Act; to enable the Scottish Ministers to form, participate in and provide assistance to companies for the purpose of providing facilities or services for persons exercising functions under the National Health Service (Scotland) Act 1978 or of making money available to the health service in Scotland

Social Care (Self-directed Support) (Scotland) Act 2013

An Act of the Scottish Parliament to enable local authorities to provide support to certain carers; to make provision about the way in which certain social care services are provided by local authorities; and for connected purposes.

Vulnerable Witnesses (Scotland) Act 2004

An Act of the Scottish Parliament to make provision for the use of special measures for the purpose of taking the evidence of children and other vulnerable witnesses in criminal or civil proceedings; to make provision about the admissibility of expert psychological or psychiatric evidence as to subsequent behaviour of the complainer in criminal proceedings in respect of certain offences to make provision about the admissibility of certain evidence bearing on the character, conduct or condition of witnesses in proceedings before a sheriff relating to the establishment of grounds of referral to children's hearings; to abolish the competence test for witnesses in criminal and civil proceedings; and for connected purposes.

Wales

The Mental Health (Wales) Measure 2010

This measure places new legal duties on local health boards and local authorities in Wales in relation to the assessment and treatment of mental health problems. The Measure became law in December 2010 and there are 4 parts to it which are as follows:

- Part 1 ensures that there are more mental health services are available within primary care.
- Part 2 makes sure all patients in secondary services have a Care and Treatment plan.
- Part 3 enables all adults discharged from secondary services to refer themselves back to those services.
- Part 4 supports every in-patient to have help from an independent mental health advocate if wanted.

Social Services and Well-being (Wales) Act 2014

An Act of the National Assembly for Wales to reform social services law; to make provision about improving the wellbeing outcomes for people who need care and support and carers who need support; to make provision about co-operation and partnership by public authorities with a view to improving the wellbeing of people; to make provision about complaints relating to social care and palliative care; and for connected purposes.

Violence against women, Domestic Abuse and Sexual Violence (Wales) Act 2015

An Act of the National Assembly for Wales to improve arrangements for the prevention of gender-based violence, domestic abuse and sexual violence; to improve arrangements for the protection of victims of such abuse and violence; to improve support for people affected by such abuse and violence; and to require the appointment of a National Adviser on gender-based violence, domestic abuse and sexual violence.

Well-being of Future Generations (Wales) Act 2015

An Act of the National Assembly for Wales to make provision requiring public bodies to do things in pursuit of the economic, social, environmental and cultural wellbeing of Wales in

a way that accords with the sustainable development principle; to require public bodies to report on such action; to establish a Commissioner for Future Generations to advise and assist public bodies in doing things in accordance with this Act; to establish public services boards in local authority areas; to make provision requiring those boards to plan and take action in pursuit of economic, social, environmental and cultural wellbeing in their area; and for connected purposes.

Appendix 2 – Websites and further information

British Psychological Society – www.bps.org.uk

The Society website has guidance, advice and further information on many topics not covered in these guidelines as well as those mentioned.

Psychologists working in clinical fields will also need to take account of Clinical Guidelines produced by NICE in England and Wales https://www.nice.org.uk/ or SIGN in Scotland http://www.sign.ac.uk/

1.1 Legal and professional obligations of psychologists

HCPC – http://hcpc-uk.org
The Health and Care Professions Council website has lots of information about professional registration including the standards of proficiency for the seven protected titles and information about indemnity insurance

Information Commissioner's Office – https://ico.org.uk/
The ICO website contains lots of useful information for organisations, private practitioners and the public regarding the rights and responsibilities under the data protection and Freedom of Information Acts.

DBS Checks – https://www.gov.uk/disclosure-barring-service-check
The government website provides helpful information for employers regarding these checks.

1.2 Continuing professional development

The HCPC has provided guidance regarding CPD for registrants. http://www.hcpc-uk.org/cpd

2.1 Working environment

Lone Working

Suzy Lamplugh Trust – http://www.suzylamplugh.org/

The Suzy Lamplugh Trust campaigns for personal safety and has lots of advice for people working alone to help to keep safe. They have some good advices and resources available.

Harassment and Bullying

ACAS – http://www.acas.org.uk/
The Advisory, Conciliation and Arbitration Service (ACAS) is a statutory organisation providing help and advice for employers and employees. They have produced guidance on several topics including harassment and bullying aimed separately at employers and employees.

Whistleblowing

Whistleblowing for employees – https://www.gov.uk/whistleblowing

The government has produced some guidance for employees surrounding whistleblowing including what to do and what to expect.

2.2 Working in the digital age

Health Insurance Portability and Accountability Act of 1996 (HIPAA) – http://www.hhs.gov/hipaa/

This American act makes provisions for health information privacy. The government website provides information for professionals regarding this act.

N.B This Act is ONLY law for practice in America.

Social Media

The HCPC has provided guidance regarding the use of social media by professional psychologists.

http://www.hcpc-uk.org/Assets/documents/100035B7Social_media_guidance.pdf

3. Safeguarding

Statutory guidance Working together to safeguard children – https://www.gov.uk/government/publications/working-together-to-safeguard-children–2
Statutory guidance on inter-agency working to safeguard and promote the welfare of children.

Getting it Right for Every Child (GIRFEC) and the Early Years Framework – http://www.maternal-and-early-years.org.uk/getting-it-right-for-every-child-principles-and-values
This is an NHS Scotland approach which establishes the principle of giving all children and young people the best possible start in life as a priority for all services.

UK Government Guidance – https://www.gov.uk/government/publications/no-secrets-guidance-on-protecting-vulnerable-adults-in-care
No Secrets sets out a code of practice for the protection of vulnerable adults.

It explains how commissioners and providers of health and social care services should work together to produce and implement local policies and procedures. They should collaborate with the public, voluntary and private sectors and they should also consult clients, their carers and representative groups. Local authority social services departments should co-ordinate the development of policies and procedures.

Protection of vulnerable adults scheme (POVA) – http://www.scie.org.uk/publications/guides/guide03/law/adults.asp
Individuals should be referred to, and included on, the POVA list if they have abused, neglected or otherwise harmed vulnerable adults in their care or placed vulnerable adults

in their care at risk of harm. By making statutory checks against the list, providers of care must ensure they do not offer such individuals employment in care positions. POVA checks are requested as part of disclosures from the Criminal Records Bureau.

Prevention and Protection in Partnership 2015 – https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/adult-safeguarding-policy.pdf

This policy from Northern Ireland is for all organisations working with, or providing services to, adults across the statutory, voluntary, community, independent and faith sectors. It sets clear and proportionate safeguarding expectations across the range of organisations.

Modern Slavery and the national referral mechanism (NRM) – https://www.gov.uk/government/collections/modern-slavery
These pages provide details about the government's work to end modern slavery, including details about how to refer victims into the NRM.

Let's talk about it – http://www.ltai.info/about/
Let's Talk About It is an initiative designed to provide practical help and guidance to the public in order to stop people becoming terrorists or supporting terrorism.

4. Managing data and confidentiality

Information Commissioners Office – https://ico.org.uk/
The Information Commissioners Office produces guidance with regards to data sharing and the Data protection and Freedom of information Acts.

HCPC guidance on confidentiality – http://www.hcpc-uk.co.uk/assets/documents/100023F1GuidanceonconfidentialityFINAL.pdf
The HCPC has provided guidance on confidentiality for registrants.

NHS – https://digital.nhs.uk/article/402/Information-Governance
The NHS has produced guidance regarding Information Governance and security for NHS and partner organisations. The NHS has codes of practice for Records management and Confidentiality.

Caldicott Report – https://www.gov.uk/government/publications/the-information-governance-review
A review was commissioned in 1997 by the Chief Medical Officer of England owing to increasing concern about the ways in which patient information is being used in the NHS in England and Wales and the need to ensure that confidentiality is not undermined. Such concern was largely due to the development of information technology in the service, and its capacity to disseminate information about patients rapidly and extensively. A committee was established under the chairmanship of Dame Fiona Caldicott. The Caldicott Report highlighted six key principles, and made 16 specific recommendations. In 2012 Dame Caldicott produced a follow up report which made 26 further recommendations including the addition of a seventh principle.

Psychological Testing Centre – http://ptc.bps.org.uk/ptc/guidelines-and-information

The PTC website contains lots of guidance about psychometric testing and the management of data generated from those tests.

5. Transparency and duty of candour

Care Quality Commission – http://www.cqc.org.uk/sites/default/files/20150327_duty_of_candour_guidance_final.pdf
The CQC has produced Information for all providers: NHS bodies, adult social care, primary medical and dental care, and independent healthcare with regards to duty of candour.

Appendix 3 – How this document has been developed

In developing these guidelines, the overall aim and scope of the guidelines was considered at length, and the decision arrived at that they should be applicable to all psychologists irrespective of registration status or practice context. The guidelines have therefore been written in a way which it is hoped is inclusive of the various contexts of practice. Drawing on a broad stakeholder group for the development work, the guidelines aim to cover all the important considerations for practice. It is however recognised they cannot cover every circumstance and also that new issues arise which will require careful consideration by the individual psychologist.

The Practice Guidelines development Working Group was constituted to include all of the member networks of the Society whose members engage in practice, including the HCPC registered practitioners. It included representatives of the Society's national branches in Scotland, Wales and Northern Ireland, in order to ensure applicability to the different national contexts. It also included representation from the expert working groups of the Society's Professional Practice Board and others on specialist topics of practice.

The content of the guidelines has been developed from a combination of revision of the previous edition in the light of professional consensus on current expectations of a good standard of practice of psychology; inclusion of key points from other Society guidance on specific topics with reference to further guidance; and in some cases development of new material drawing on the professional experience of our members or outside professionals in the field. The working group has not used systematic methods to search for or assess the evidence for the material included. Recommendations have been included based on working group consensus. Where there are known areas of professional difference of opinion this has been stated.

A draft of the guidelines was circulated for Society wide consultation and one month allowed for comment. This included circulation to Experts by Experience (psychology service user representatives) with whom the Society works in various contexts. The Guidelines were also sent for comment to the Health and Care Professions Council as the statutory regulator for practitioner psychologists. Comments received were considered carefully by the Working Group and changes made to the text of the guidelines where considered necessary. The annotated audit sheet of the comments received and disposal was provided to a meeting of the Society's Professional Practice Board to assist its consideration of the draft guidelines, by way of final peer scrutiny. The guidelines were reviewed by the Society's legal advisers prior to publication. Final approval of the guidelines was given by the Society's Board of Trustees.

The guidelines will be reviewed and updated in accordance with Society policy after five years or sooner if circumstances indicate this is needed.

To ensure clarity and presentation in a user friendly format, the Guidelines have been edited by professional staff within the Society and the format designed by the Society's Preparation for Print specialists. Where considered helpful, links have been made to

additional web based resources, both to assist practitioner development and to provide up to date information in areas where there is frequent change. Organisational providers of psychological services are encouraged to review how these guidelines are used in practice and feed back to the Society any barriers to application.

In ensuring an appropriate level of independence in the production of these Guidelines, the Society has ensured its conflict of interest policy has been complied with and that no member of the working group's input has been compromised by a conflict of interest. No member has received any form of remuneration other than reimbursement of travel and subsistence expenses in accordance with Society policy. The large size of the working group and peer scrutiny and challenge, as well as the robust consultation process, guards against the potential for any one member or small group of members inappropriately to bias the Guidelines.

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Learning Disability: Definitions and Contexts



Professional Affairs Board of
The British Psychological Society

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Membership of the Working Group

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Introduction

Following the introduction of new and revised mental health and local government legislation in the 1980s[1], the British Psychological Society published a guidance document, *Mental Impairment and Severe Mental Impairment: A Search for Definitions* (BPS, 1991). This document highlighted the different definitions used within the respective Acts, and offered guidelines on operational criteria. The document was generally well received within the profession and was followed, in 1995, by a similar paper relating specifically to the Mental Health (N. Ireland) Order 1986.[2]

The original documents focused on specific pieces of legislation which used the terms *'(severe) mental impairment'* and *'(severe) mental handicap'*. This led to some debate regarding the need for a broader document with respect to 'learning disability' and its relation to other legislation in a wider context. As a result, the Society's Professional Affairs Board invited the Special Interest Group (Learning Disabilities) of the Division of Clinical Psychology to look again at these documents, with a view to updating and, where appropriate, amending them to cover a broader field. This document is the result of that review.

The guidelines presented in this document are not intended to be sufficient for a full psychological assessment for adults with learning disabilities. The nature of any such assessment would obviously depend on individual circumstances but, within most contexts, reliance solely on overall figures derived from assessments of intellectual functioning and / or other norm-based assessments would have limited value.[3] Indeed, presenting an overall figure derived from such assessments may be misleading and potentially damaging, particularly if used in any predictive sense.[4] Psychologists should be sensitive to the issues related to labelling[5] – particularly in terms of test scores alone – and should resist simplistic interpretations of an individual's need based on broad classifications.

There has been a welcome trend away from assessments based exclusively on psychometric test results which lead solely to simple classification and categorisation of 'learning disability', to one which seeks to assess individual need and to identify the necessary supports to meet that need.[6]

[1] The Mental Health Act 1983, the Mental Health (Scotland) Act 1984, the Abolition of Domestic Rates (Scotland) Act 1987 and the Local Government Finance Act 1988.

[2] British Psychological Society (1995). *Mental Handicap, Severe Mental Handicap and Severe Mental Impairment: The Mental Health (N.Ireland) Order 1986. Definitions and Operational Guidelines.*

[3] It is accepted that the use of such instruments to *profile* abilities, particularly within a neurological context, does have value and, used in this way, such, well chosen, assessments afford people with learning disabilities access to the same type of service provided for people with disorders of neurological functioning but who do not have learning disabilities. However, within this context, it would be the interpretation of the *range* of scores that would be of importance, not the overall figure *per se.*

[4] This point is relevant in all areas but particularly so for children and young adults.

[5] Labelling can be socially devaluing. Equally, it can be argued that it is not the labelling *per se* which is of prime significance but the *social consequence* of the labelling. Construed in this way, meaningful change for individuals would include change within the wider social and political systems (see Bell, 1989; Szivos, 1992; Brown & Smith, 1992, for general discussion).

[6] The American Association on Mental Retardation (AAMR, 1992) avoids reliance on IQ scores to assign a level of disability by suggesting a framework which relates the person's needs to the intensities of *'... the supports necessary to enhance their independence/interdependence, productivity and community integration.'* However, even under this system, there is an agreed definition of Mental Retardation which does rely on assessments of intellectual and social functioning.

To be valid, a psychological assessment needs to be based on a comprehensive analysis, including reference to biological, psychological and interactional factors, within the broader social / cultural and environmental context.

As the concept of learning disabilities may be seen as a social construction[7] – even when the biological / neurological basis is known – the idea of any permanency of the concept must be questioned, as the phenomenon of IQ drift, and its changing criteria, clearly illustrate.

However, *given* its social construction, and whatever one's views are on its theoretical basis, it has to be acknowledged that the concept is enshrined within our social and legal systems. As such, the concept affects peoples' legal and civil rights.

Some psychologists may find that the concept of classification presents some personal difficulties, particularly as it may have lasting implications on an individual's life. Over time many injustices have been done to people labelled as *different*. However, there are situations in which an opinion on classification can assist a person to gain access to civil and legal rights and protections. For example, to prove discrimination, to argue against denial of an 'appropriate adult' during police questioning[8], to consider a case under the Sexual Offences Acts 1956[9] / 1967, at some point it may be appropriate to consider whether a person could be seen to have a *(severe)* learning disability. Without acknowledgement of the disability a person might be denied rights to justice and / or equality.

This document was proposed in response to an expressed need for guidance on how the concept of learning disabilities, as used within a health and personal social services setting, relates to its use in civil, legal and medico-legal contexts.

Much of the content of the Society's original documents has been retained. The Society wishes to reaffirm its view that the guidance offered should be used both with caution and in full knowledge of the limitations of classification within specific contexts.

[7] See Clements (1998) for discussion.

[8] Under the Police and Criminal Evidence Act 1984 (PACE).

[9] For Scotland, Mental Health (Scotland) Act 1984 (s 106).

Scope of the Current Guidelines

The functions of this document are to outline the features that make up the definition of 'learning disability', as used within a health and social care context, and to introduce the complexities of the use of that term in a variety of other contexts. Recommendations regarding good practice are also included.

There are a number of areas *not* covered by these guidelines, one of which is 'mental (in)capacity'. This is a legal concept, involving a person's ability to make informed decisions (e.g. about medical treatments, financial matters, contracts, wills, etc.). Clearly, there is a relationship between intellectual ability and mental capacity. However, 'learning disability' and 'mental incapacity' are *not* synonymous, and it is possible for someone to have a 'learning disability' and yet also to be deemed as 'mentally capable'.[10] Further, mental incapacity may arise for reasons other than learning disability (e.g. dementia, mental illness, acquired brain damage in adulthood, etc.). Any assessment relating to mental incapacity or consent should not rely on generalised inferences relating to the broad categorisation of people. Assessments for this purpose should always be conducted within the context of the particular issue in question and of the particular individual concerned.[11]

Equally, even if an assessment is made with respect to classification, it is unlikely – except in certain instances[12] – that this will be sufficiently comprehensive or meaningful. Further work would be required to assess exactly how the learning disability might affect a person's performance within the relevant setting, and what additional supports he/she might need.[13] Again, discussion on the range of assessment required within this context falls outside the scope of these guidelines.

This document deals only with *adults* with learning disabilities, and as such specifically excludes discussion on legislation and assessment relating to children. Guidance on the assessment of children is available elsewhere within the Society.[14]

Owing to the different legislative systems, some difficulties are encountered when producing one document that is relevant for use throughout the UK. Because of this, Part 2 of this document, *Associated Contexts,* makes some compromises and, thus, focuses on commonalities (whilst *highlighting* differences) between the respective UK legislation. Readers requiring specific detail on a particular piece of legislation should refer to the appropriate Statute.

[10] Williams (1995) notes that there '*…should be an assumption that witnesses with learning disabilities are competent, both in law and in practice, and that the burden of proof for determining otherwise should be put on the party challenging competence*'.

[11] Command Paper Cm 3803 (1997); Command Paper Cm 4465 (1999); Cohen (1998); Gelsthorpe (1998).

[12] Perhaps within the context of the Sexual Offences Acts 1956/1967.

[13] For example, as a witness in court (see Sanders *et al.,* 1996).

[14] Contact the Division of Educational and Child Psychology and the Division of Clinical Psychology, Special Interest Group – Children and Young People.

Part 1: Defining 'Learning Disability'[15]

People with learning disabilities do not constitute an homogeneous group. However, in terms of diagnosis and classification there are a number of features of learning disability which have gained widespread acceptance across professional boundaries within the UK and America.[16] Irrespective of the precise terminology, or the wording in the various definitions, there are three core criteria for learning disability:

- **Significant impairment of intellectual functioning;**
- **Significant impairment of adaptive/social functioning;**
- **Age of onset before adulthood.**

All three criteria must be met for a person to be considered to have a learning disability (see Appendix I for further details of the main clinical definitions).

Difficulties in assessing adaptive / social functioning have contributed, in the past, to a tendency amongst clinicians to concentrate on assessment of intellectual functioning only. The assumption has been that, provided a significant impairment of intellectual functioning has been demonstrated, similar deficits in adaptive / social functioning are likely. However, this is not always the case.

The Society recommends that, in accordance with the various definitions, classification of learning disability should only be made on the basis of assessed impairments of both intellectual and adaptive/social functioning which have been acquired before adulthood.

1.1 ASSESSMENT OF IMPAIRMENT OF INTELLECTUAL FUNCTIONING

The principal method for determining levels of intellectual functioning still remains psychometric assessment. Assessments which are based on an explicit model of normal distribution of general intelligence are the procedures of choice.

Assessment of general intellectual functioning, for clinical, medico-legal and other purposes, should be obtained through the use of an individually administered test which is recognised as being reliable, valid and properly standardised. The test employed in any given case must be appropriate for the person's age, cultural, linguistic and social background.

[15] At present, within the UK, *learning disability/disabilities* is the terminology with the greatest currency and, within the context of health and social care, has largely replaced the term *mental handicap* – although *mental handicap* is still used in the Mental Health (N Ireland) Order, 1986. *Intellectual disabilities* is favoured by some authorities – but using this terminology, there is a danger that the concept could be construed solely as one relating to intellectual impairment (i.e. excluding the aspect of adaptive/social functioning). The term *mental retardation* is in common usage in North America.

[16] American Association on Mental Retardation, 1992; World Health Organisation, 1992 (ICD-10); American Psychiatric Association, 1994 (DSM-IV); Department of Health, 1998.

Using tests based on a normal distribution of general intelligence, significant impairment of intellectual functioning has, by convention, become defined as a performance more than two standard deviations below the population mean. On the Wechsler Adult Intelligence Scale – Revised (WAIS-R) (Wechsler, 1981; Lea, 1986), the most commonly used measure of general intellectual functioning for the adult population, and the more recently published WAIS-III^{UK} (Wechsler, 1999), the mean is 100 and the standard deviation is 15. More than two standard deviations below the mean thus corresponds to an Intelligence Quotient (IQ) of 69 or less.[17]

IQ scores for individual cases should always be quoted with explicit confidence limits. Confidence limits represent the probable extent of measurement error for scores derived from a particular test. On the Wechsler scales, the 95 per cent confidence limits vary with age group and measured IQ level (see Appendix III).

When conducting psychometric assessments of intellectual functioning, careful consideration should be given to differentiating between performance which is due to learning disability and performance which is impaired by other factors. For example, the presence of emotional / psychological distress (or other psychological / psychiatric factors), medication, alcohol or other drugs, may have consequences in terms of (perhaps, temporary) diminution in performance. Similarly, caution will need to be exercised regarding the assessment of individuals with cognitive impairments acquired during adulthood as a consequence of neurological trauma or disease. These acquired impairments may exhibit through generalised flattening of scores, or extreme variability in IQ or test Index or sub-test scores, or through specific deficits.

The findings from these assessments should always be interpreted in the light of knowledge of the individual's personal, cultural circumstances, clinical status and other assessment information, and with a sound knowledge of the uses and limitations of such assessment methods.

The Society notes that psychometric test results, in particular, are open to misrepresentation or inappropriate usage. In order to achieve the best possible understanding of the technical information given, and to avoid misuse, non-psychologist readers of this document are encouraged to make use of available help from a qualified psychologist whose credentials are recognised by the profession, i.e. a Chartered Psychologist.

1.2 IMPAIRMENT OF ADAPTIVE/SOCIAL FUNCTIONING

1.2.1 DEFINITION OF ADAPTIVE/SOCIAL FUNCTIONING

The concept of adaptive / social functioning is very broad and relates to a person's performance in coping on a day-to-day basis with the demands of his / her environment. It is, therefore, very much related to a person's age and the socio-cultural expectancies associated with his / her environment at any given time. It is concerned with what a person *does* (i.e. actual behaviour / performance).

[17] The 'cut-off' for 'learning disability' of an IQ of 69 is in line with both ICD-10 and DSM-IV (see Appendix I): the former states that *'an IQ of 69 or below is indicative of mental retardation'*, while the latter notes that the *'disorder is characterised by significantly sub average intellectual functioning (an IQ of approximately 70 or below)'*. It should be noted, however, that any overly strict cut-off criterion would not fully reflect the limitations inherent within each test. Informed clinical judgement would be required especially around transitional cut-off points.

The concept of *'adaptive functioning'* has been further refined by reference to its component parts. Both the American Association on Mental Retardation (AAMR, 1992) and DSM-IV[18] adopt a criterion of impairments in 'at least two' of the following areas: *communication, self-care, home living, social/interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure, health and safety.* The use of *'at least two'* impairments as a criterion may, however, produce some anomalies, with little face validity. For example, in the case where, perhaps, only *work* and *leisure* are impaired (with other skills intact), the extent of the overall impairment of adaptive skills may be questioned. Additionally, the DSM-IV gives no guidance concerning the *severity* of impairment within the respective areas.

Within the context of 'mental impairment', the BPS document (1991) focused on the concept of *'social functioning'*, which included only those skills that may be considered as *personal life survival skills* – other skills, related more to interpersonal / cultural / social aspects of day-to-day living, and alluded to in other definitions, were omitted.[19,20,21] By excluding wider aspects of social / community adaptation, it is now considered that the previous BPS definition (1991) is unduly restrictive. By broadening the criteria, it is accepted that the tightness of the previous definition has been lost. Nevertheless the following is recommended:

***Impairment of Adaptive/Social Functioning* – The individual requires significant assistance to provide for his/her own survival (eating and drinking needs and to keep himself/herself clean, warm and clothed), and/or with his/her social/community adaptation (e.g. social problem solving, and social reasoning).**

The degree of assistance required may vary in terms of intensity (e.g. physical or verbal prompting) and frequency (e.g. daily or less often than daily), but the required assistance should always be outside the range of that expected within the individual's particular culture / community.

1.2.2 ASSESSMENT OF ADAPTIVE/SOCIAL FUNCTIONING

Despite the difficulties in defining adaptive / social functioning, there exists a variety of scales purporting to measure it. These are completed usually by direct observation and / or in conjunction with at least one informant who knows the person well (for example, a parent, carer or friend).

[18] *Diagnostic and Statistical Manual of Mental Disorders* – 4th Edition (American Psychiatric Association, 1994).

[19] Gunn (1996) notes that, from a legal perspective, *'social functioning … includes such matters as: ability to care for oneself; personal hygiene; personal and social (perhaps sexual) relationships with others'.*

[20] Nunkoosing (1995) cites two components: *'personal independence'* (being able to sustain oneself in everyday living activities) and *'social responsibility'* (being able to conduct oneself appropriately in social situations).

[21] AAMR (1992) refers to two facets of social functioning: *'practical intelligence'* and *'social intelligence'.*

Assessments of adaptive / social functioning may be norm-referenced, criterion-referenced and those of the skills checklist variety.[22,23] The use of any one such assessment should be considered only after some scrutiny, and with reference to the specific item content, as some scales consist of items that may extend the definition of adaptive / social functioning beyond that given above.[24]

An assessment of adaptive / social functioning must be made with reference to the person's age, gender, socio-cultural background, religion and community setting. To be relevant, within the context of learning disability, any impairment of adaptive / social functioning must not *solely* be a consequence of other disabilities (e.g. physical illness, mental health problems or sensory impairment).

Despite the inherent difficulties with many such instruments, the use of a formal assessment of adaptive/social functioning should be seen as good practice. At least one assessment (preferably completed with more than one informant, and on more than one occasion) should be carried out.

The Society believes that there is not, as yet, sufficient consensus within the area for one single assessment to be recommended. Judgement will need to be made based on item analysis of the assessment and on the significance of any impairment (see Section 1.4.2).

1.3 AGE OF ONSET

For a person to be considered to have a learning disability, significant impairments of intellectual and adaptive / social functioning must have been acquired during the developmental period. There is some consensus that the Age of Onset criterion is *below 18 years*.[25,26] However, there is some concern, shared by many clinicians, that people acquiring learning disabilities later in childhood (but before the age of 18 years) as a consequence of cerebral trauma may face different challenges than a person showing learning disabilities from infancy.

This issue may not be significant if individualised assessments are undertaken with the intention of identifying a person's support needs. However, if such assessments are simply used to serve a 'gate-keeping' function, for example (see Section 2.5 below), such a person may be disadvantaged if this results in exclusion from a more appropriate service (e.g. one designed for people with acquired brain damage).

[22] For information about the validity and reliability of the tests available, Hogg and Raynes (1987) remains a useful text although some assessments have had subsequent revisions.

[23] Those scales that list some psychometric properties and/or normative data include the *AAMR Adaptive Behaviour Scale – Residential and Community* (Nihira, Leland & Lambert, 1993); the *Vineland Adaptive Behaviour Scales* (Sparrow, Balla & Chichetti, 1984) and the *Hampshire Assessment for Living with Others (*Shackleton Bailey *et al.,* 1982).

[24] Analysis of some assessments of adaptive/social functioning reveal sub-tests of a *descriptive* nature (e.g. *Physical Disability, Posture*) rather than having an *operational* criteria – the former may have an *influence* on adaptive functioning but do not *measure* actual behaviour/performance.

[25] Whilst both the DSM-IV and the AAMR (1992) recommend an age criterion for *Age of Onset* of before 18 years, the ICD-10 (WHO, 1992) makes no specific criterion other than *'… during the developmental period'*. Hatton (1998) draws attention to the cultural nature of this age criterion.

[26] Given its cultural nature, and with reference to Sexual Offences legislation, theoretically there may be some advantage to linking this age of onset criterion to the 'age of consent' for sexual relationships. However, this would also lead to major discrepancies, particularly with respect to the variable ages of consent in different countries (even within the UK) and/or where age of consent is dependent on gender and/or type (heterosexual or other) of sexual relationship.

In order to determine the most appropriate service support, it is recommended that the effect of acquired impairment on a previously higher, non-impaired level of functioning is taken into account. Particular reference should be made to any profile of psychometric sub-test scores that would indicate, clinically, that the person's abilities would be more appropriately construed as specific brain / neurological damage.

The Society recommends that in all cases where a medical condition or trauma is present, the age this occurred should be documented, whether before birth, at birth or during childhood.

Age of onset before adulthood may be demonstrated by historical evidence from medical records (e.g. developmental milestones), educational records such as a Statement of Educational Need, or records of previous use of specialist health and social services. However, it is always possible for an individual to have 'slipped through the net'. Any historical information needs to be interpreted with care as functioning can change over time and the results of different psychometric assessments are usually not directly comparable.

1.4 SYSTEMS OF SUB-CLASSIFICATION

Within the clinical context, sub-classifications of *mild, moderate, severe and profound* 'mental retardation' are used in two main classification / diagnostic manuals.[27] Although these systems employ the same descriptive categories, the quoted IQ ranges do not correspond exactly.

It is notable that the AAMR (1992) no longer uses these four clinical sub-categories, favouring instead a classification system of 'mental retardation' which specifies *the level of support required within respective areas of functioning.* Such a system is seen by the Association as being '*…more functional, relevant, and orientated to service delivery and outcomes than the labelling system currently in use.'*

Traditionally, in the UK, two (occasionally three) categories of learning disability have been favoured.[28,29] However, more recently, the Department of Health (1999) has referred to *mild, moderate, severe* and *profound* learning disabilities, reflecting the categorisations in the classification / diagnostic manuals.[30]

The operational guidance issued by the Society in 1991 did not comment on sub-classification of learning disability *per se* but made a two-category subdivision into *significant* and *severe* impairments of intelligence and social functioning in the context of mental health legislation categories of 'mental impairment' and 'severe mental impairment'.

The Society recommends that decisions involving sub-classification of 'learning disability' should make reference to both intellectual and to adaptive/social functioning using the criteria below as guidance. Furthermore, it is considered good practice to make reference to the levels of supports required.

[27] ICD-10 (1992) and DSM-IV (1994)

[28] DHSS/Welsh Office (1971); National Development Group (1977); DHSS (1980); Audit Commission (1988); DoH, (1992).

[29] For more recent discussion see Dodd & Webb (1998).

[30] See also Evers & Hill (1999) and, in contrast, Dodd & Webb (1998).

1.4.1 SUB-CLASSIFICATION OF IMPAIRMENT OF INTELLECTUAL FUNCTIONING

In line with the previous BPS document (1991), *significant* impairment of intellectual functioning is considered to be represented by an IQ between two and three standard deviations below the population mean, and *severe* impairment of intellectual functioning is considered to be represented by an IQ of more than three standard deviations below the mean. On the most commonly used measures of intellectual functioning (the Wechsler scales), with a standard deviation of 15 points, these cut-off points correspond to IQs of <70 and <55 respectively:

Significant Impairment of Intellectual Functioning: IQ 55-69
Severe Impairment of Intellectual Functioning: IQ <55

Again, it is noted that owing to errors of measurement[31] there is some flexibility around these transition points (see Appendix III).

Whether based on standard deviations (as in DSM-IV) or arbitrary cut-offs (as in ICD-10) the use of fine-grained sub-divisions below an IQ of approximately 55, in the case of adults, depends on IQ figures which are hypothetical or extrapolated. There seem to be no reliable or valid psychometric instruments, for the adult population, to enable the clinician to arrive at the IQ figures needed to make these distinctions. Thus sub-classification on the basis of IQ scores from directly administered IQ tests cannot be carried out reliably for the lowest levels of intellectual functioning.

In practice, some clinicians are known to use child development scales or children's intelligence tests to profile aspects of intellectual functioning of very disabled adults. Whilst, clinically, this may have some use in assessing performance on specific tasks, attempts to derive extrapolated IQ scores from the use of developmental scales or child intelligence tests constitutes extremely dubious practice and is not recommended. Likewise, the practice of referring to 'mental age' when reporting on the level of intellectual or social functioning of adults should be avoided.

Note: In early versions of the WAIS-III^{UK} manual, the section on '*Diagnosing Severe Learning Disability*' quotes the criteria for *significant* (i.e. not *severe*) learning disability. This is an error.

1.4.2 SUB-CLASSIFICATION OF IMPAIRMENT OF ADAPTIVE/SOCIAL FUNCTIONING

The operational guidance issued by the Society in 1991 distinguished between requiring 'partial help' (a *significant* impairment) and 'continued assistance' (a *severe* impairment). However, this guidance did not define the difference between these two levels of help. How the degree of adaptive/social impairment is associated with *level* of learning disability has led to some debate. Dodd and Webb (1998) suggest using certain score profiles on the HALO (Shackleton Bailey *et al.*, 1982) to distinguish between *significant* and *severe* impairment of social functioning. The Vineland Adaptive Behaviour Scales (Sparrow *et al.*, 1984) classifies 'adaptive' levels into 'mild, moderate, severe and profound deficit' on the basis of standard scores.

[31] Approximately ± 5 IQ points on the Full Scale scores of the WAIS-R (Wechsler, 1981).

Given the presented definition of adaptive/social functioning and the item content of the many scales which profess to measure the concept, no one particular assessment can, at this stage, be recommended for determining levels of adaptive/social functioning. However, when making a judgement as to the degree of impairment of adaptive/social functioning, the following levels of support (AAMR, 1992) are considered useful as a guide:[32]

Intermittent	Supports on an 'as needed basis'. Characterised by episodic nature, person not always needing the support(s), or short-term supports needed during life-span transition (e.g. job loss or an acute medical crisis). Intermittent supports may be high or low intensity when provided.
Limited	… supports characterised by consistency over time, time-limited but not of an intermittent nature, may require fewer … [resources] than more intense levels of support …
Extensive	Supports characterised by regular involvement (e.g. daily) in at least some environments (such as work or home) and not time-limited …
Pervasive	Supports characterised by their consistency, high intensity; provided across environments; potential life-sustaining nature …

When determining level of impairment of adaptive/social functioning, the following may be used as a guide:

- **Intermittent and Limited support indicate a sig*nificant im*pairment of adaptive/social functioning;**
- **Extensive and Pervasive support indicate a se*vere im*pairment of adaptive/social functioning.**

It should be stressed that the above is presented as a *guide*.[33] The judgement will rest on both the intensity of the assistance (e.g. verbal or physical prompting, or carrying out tasks on the individual's behalf) and on its frequency (e.g. daily or less often than daily); the required assistance should always be outside that range of that expected within the individual's particular culture/community.

[32] For the complete tabulated descriptions refer to *Mental Retardation: Definition, Classification, and System of Supports – 9th Edition* (AAMR, 1992).

[33] The categories of support defined by AAMR (1992) generally reflect both the *frequency* and *intensity* of support – although not consistently so. With respect to intensity, the *Intermittent* and *Pervasive* categories contain relatively clear operational criteria; the *Limited* category contains some reference, whereas the *Extensive* category contains no reference. Particularly with these latter two categories, a judgement will have to be made based on the criteria which appear in the other categories. The criteria for frequency is more consistent, ranging from an 'as needed basis' for *Intermittent* to their 'constancy' for Pervasive support.

1.4.3 REQUIREMENT FOR CONCURRENCE OF THE TWO IMPAIRMENTS

Learning disability requires that significant impairments of intellectual and adaptive / social functioning coexist. This means that a person with a *significant* (or even *severe*) impairment in one of the two domains only, and with no significant impairment in the other, may not be adjudged to have a learning disability.[34]

Similarly, for *severe* learning disability, severe impairments of *both* intellectual and adaptive / social functioning must be evident.

For some individuals, levels of intellectual functioning and adaptive / social functioning will be relatively consistent. For others this may not be the case.

When there is large discrepancy between intellectual functioning and adaptive / social functioning, great care must be taken during assessment – particularly when the extent of a person's impairment in intellectual and / or adaptive / social functioning is near the boundary between *severe* and *significant*, or between *significant* and *non-significant*. Bearing in mind the limits in rigour of, especially, adaptive / social functioning assessments, it is in these circumstances that such judgements need to be approached with appropriate caution.

[34] DSM-IV (1994) notes that: *'Mental retardation would not be diagnosed in an individual with an IQ lower than 70 if there are no significant deficits or impairments in adaptive functioning.'*

Part 2: Associated Contexts

Learning disability, or associated terminology, appears in a wide range of contexts:

- Mental Health Legislation;
- Criminal Justice System;
- Local Government / Benefits Legislation;
- Miscellaneous.

It should be noted that within these contexts, similar terminology is often used with *different definitions* (see Appendix II). For instance, the term *severe mental impairment* under the Mental Health Act 1983 has a different definition from the same term used within local government legislation. Thus, it is important to ensure that the specific context in which any classification occurs is made explicit, and that classification in one particular context does not imply classification in any other.

In addition, many legal classifications, whilst appearing similar, should not be confused with clinical or psychological classification. It must be accepted that the context is different. However, within a legal context, clinical or psychological terminology may justifiably be used to assist the Court to make its judgement.

Within contexts other than the purely clinical it is important that the psychologist should first identify the appropriate clinical classification, and then judge how this relates to the specific definition used within the applied context.

Above, we have argued that classifications used by psychologists can be valid and justified within certain contexts. Equally we would argue that, in certain contexts, classification *per se* has no valid role – it would be important to recognise other factors that are more significant than inferences drawn from broad classifications.

As was mentioned above (page 3), owing to the complexities of relating the different legislative systems to each other, some compromises have been necessary in order to produce one document which is equally relevant throughout the UK. Thus, in this section, the document draws mainly on the commonalities between the respective UK legislation. Where significant differences occur, these are highlighted, but readers requiring more specific detail on a particular piece of legislation should refer to the appropriate Statute.

2.1 MENTAL HEALTH LEGISLATION

This part of the document relates to those categories that appear within the respective Mental Health Acts / Orders, throughout the UK, and which pertain to Admission for Assessment and for Treatment under the Acts / Orders.

With respect to the Assessment and Treatment sections that are potentially relevant to people with learning disability there is much similarity between the Mental Heath Act, 1983 (England & Wales) and the Mental Health (Scotland) Act 1984.[35]

There are, however, differences between these Acts, specifically relating to crimes *against* the person who is subject to the Act. For instance, in addition to the sections relating to Assessment and Treatment, the Mental Health (Scotland) Act 1984 includes a range of legislation relating to unlawful sexual intercourse with women with 'mental handicap'.[36,37] Sections relating to aspects other than Admission for Assessment and Treatment are further discussed in Section 2.2 of this present document.

The categories in the Mental Health (N.Ireland) Order 1986 differ from the above Acts. These are discussed in Section 2.1.3 below.

The 'conduct' criterion (i.e. abnormally aggressive and / or seriously irresponsible conduct) which appears in the definitions of *mental impairment* and *severe mental impairment* appears in certain categories in all the Acts / Orders, and is further discussed in Section 2.1.4 below.

2.1.1 MENTAL HEALTH LEGISLATION' ENGLAND AND WALES

The Mental Health Act 1983 uses the term mental disorder which is defined as:

> *mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of mind.*

Although the phrase *arrested* or *incomplete development of mind* is relevant to people with learning disabilities, for many purposes of the Act it is not sufficient that a person is suffering from mental disorder *per se* but from one of the four *specific* categories of mental disorder specified in the Act. The main two categories that are potentially relevant to people with learning disabilities are *mental impairment* and *severe mental impairment.*

Although related, the terms *mental impairment* and *severe mental impairment* are not synonymous with 'learning disability'. Under this Act these terms are defined as follows:

- Mental Impairment:
  … a state of arrested or incomplete development of mind not amounting to severe mental impairment which includes significant impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned. [s 1(2)]
- Severe Mental Impairment:
  … a state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned. [s 1(2)]

[35] Under the definition of 'mental disorder', the Mental Health (Scotland) Act 1984 does not contain specific reference to 'psychopathic disorder' or to 'any other disorder or disability of mind' which appears in the Mental Health Act 1983.

[36] Reference to homosexual acts appears in the Criminal Justice (Scotland) Act 1980.

[37] Similar, but not directly comparable, legislation appears, in England, in the Sexual Offences Acts.

These definitions of *mental impairment* and *severe mental impairment* make reference to two of the three 'core' criteria for learning disability (i.e. *significant/ severe impairment of intelligence* and *social functioning*) but also include a criterion of '*abnormally aggressive or seriously irresponsible conduct'*.

Again, it should be emphasised that these terms are legal classifications, to be used for the purposes of the Act, and as such are distinct from medical / clinical terminology.[38] As the criteria specified in the Act are not further defined, the importance of clinical judgement is acknowledged. The Mental Health Act 1983 Memorandum[39] notes that:

> *The distinction between 'severe mental impairment' and 'mental impairment' is one of degree: the impairment of intelligence and social functioning is 'severe' in the former and only 'significant' in the latter. Slight impairment cannot fall within either definition. The assessment of level of impairment is a matter for clinical judgement.*[40]

Whilst the above guidance states that the assessment of degree of impairment is a matter for clinical judgement, it is the view of the Society that such a judgement should be based on a full assessment as outlined in Part 1 above (in addition to the 'conduct' criteria' see Section 2.1.4 below).

It should be noted that the *level* of mental impairment (i.e. significant or severe) is of some consequence under the Act, as different legal consequences may ensue from the respective classifications. The Mental Health Act 1983 Memorandum states:

> *This distinction between the two degrees of mental impairment is important because there are differences in the grounds on which patients can be detained, or have their detention renewed if they suffer from severe mental impairment as opposed to mental impairment.* [s.10]

With regard to assessment, the Mental Health Act 1983 Code of Practice gives the following guidance:

> *No patient should be classified under the Act as mentally impaired or severely mentally impaired without an assessment by a consultant psychiatrist in learning disabilities and a formal psychological assessment. This assessment should be part of a complete appraisal by medical, nursing, social work and psychology professionals with experience in learning disabilities…* [s.30.4]

2.1.2 MENTAL HEALTH LEGISLATION – SCOTLAND

The Mental Health (Scotland) Act 1984 also uses the term *mental disorder*, albeit defined slightly differently from the Mental Health Act 1983:

> *Mental illness, or mental handicap however caused or manifested.*

As with the Mental Health Act 1983, for most purposes of the Act it is not sufficient that a person is suffering from mental disorder *per se* but from one of the four *specific* categories of mental disorder specified in the Act. Again, the main two categories that are relevant to people with learning disabilities are *mental impairment* and *severe mental impairment*.

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[38] Gostin (1983) *A Practical Guide to Mental Health Law.* London: MIND.

[39] Department of Health and Welsh Office (1998) *The Mental Health Act 1983, Memorandum on Parts I to VI, VIII and X.* See also Department of Health and Welsh Office (1999) *Mental Health Act 1983 Code of Practice Mental Health Act.*

[40] Department of Health and Welsh Office (1999) *The Mental Health Act 1983 Code of Practice* adds that this clinical judgement should be *'… guided by current professional practice and subject to the relevant legal requirements'.*

The definitions of *mental impairment* and *severe mental impairment* are identical to the definition appearing in the Mental Health Act 1983 (see above).

2.1.3 MENTAL HEALTH LEGISLATION – NORTHERN IRELAND

The Mental Health (N. Ireland) Order 1986 defines Mental Disorder as:

> *Mental illness, mental handicap and any other disorder or disability of mind.*

The following terms, further defined in the Act, are relevant to people with learning disabilities:

- **Mental Handicap:** *a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning.*
- **Severe Mental Handicap:** *a state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning.*
- **Severe Mental Impairment:** *a state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned.*

Within this Order it should be noted that the definition of *severe mental impairment* is identical to that of *severe mental handicap*, save for an additional 'conduct' criterion.

The definition of *severe mental impairment* is identical to that of *severe mental impairment* in both the Mental Health Act 1983 and the Mental Health (Scotland) Act 1984 but unlike these two Acts, the Northern Ireland Order does not contain a category of *mental impairment*.

Since a Treatment Order in Northern Ireland can be invoked only in a case of *severe mental impairment* (with its attendant severe impairments of both intelligence and social functioning), this makes it crucial for accurate operational distinctions between *significant* and *severe* impairments to be agreed in that particular context.

2.1.4 ABNORMALLY AGGRESSIVE OR SERIOUSLY IRRESPONSIBLE CONDUCT

Abnormally aggressive or seriously irresponsible conduct are behaviours which must be associated with 'a state of arrested or incomplete development of mind' in order to meet the criteria for categorisation as *mental impairment* under the Mental Health Act 1983 and the Mental Health (Scotland) Act 1984, or in order to meet the criteria for categorisation as *severe mental impairment* under the Mental Health Act 1983, the Mental Health (Scotland) Act 1984 and the Mental Health (Northern Ireland) Order 1986.

These behaviours are not further defined within the Acts or the Order, but the Mental Health Act 1983 Memorandum[41] comments that they were included in the formulation of *mental impairment* and *severe mental impairment* so as:

> *to ensure that people with learning disabilities are not subject to long-term compulsory powers unless the behaviour which is part of their condition in that particular case justifies the use of those powers.* [s.9]

[41] Department of Health and Welsh Office (1998).

In seeking to operationalise these terms, therefore, it is appropriate to bear in mind that they should constrain, rather than maximise, the extent to which people with learning disabilities can be compulsorily detained.

The Mental Health Act 1983, Code of Practice (1999) gives the following guidance on how to assess these behaviours:

- **Abnormally aggressive behaviour:** *Any assessment of this category should be based on observations of behaviour which lead to a conclusion that the actions are outside the usual range of aggressive behaviour, and which cause actual damage and/or real distress occurring recently or persistently or with excessive severity.* [s.30.5]
- **Irresponsible conduct***: The assessment of this characteristic should be based on an observation of behaviour which shows a lack of responsibility, a disregard of the consequences of action taken, and where the results cause actual damage or real distress, either recently or persistently or with excessive severity.* [s.30.5]

Thus, the assessment of *'abnormally aggressive or seriously irresponsible conduct'* can be seen to have both observational (i.e. the actual behaviour) and judgement (i.e. the abnormality and / or seriousness) components. In this connection the previous recommendations (BPS, 1991) are developed here.

For both abnormally aggressive and seriously irresponsible conduct there should be direct observation of actual conduct / behaviour, or reported observation by at least two reliable witnesses (although in some instances no second person may be present, when this criterion for reliability cannot be met), and there should be recording of this conduct / behaviour in behavioural terms.

Abnormally aggressive conduct must be judged to be 'outside the usual range of aggressive behaviour' – unpredictability or unreasonableness *under the circumstances* will be factors which may establish the criterion.

Irresponsible conduct is that which shows a lack of responsibility and / or a disregard of the consequences of the action – it does not necessarily require the person to be capable of judging these consequences. In certain circumstances, *failure to act* can also be evidence of irresponsibility.

To met the criteria for each, abnormally aggressive and seriously irresponsible conduct should result in actual damage and / or real distress (in some cases to the self), and should occur *'either recently or persistently or with excessive severity'*.

There is a lack of official guidance on how to decide when abnormally aggressive or seriously irresponsible conduct have ceased, although the importance of being able to do so is clear. It would not be appropriate to continue to regard a person who has a learning disability as being mentally impaired, if remission or treatment have eliminated their abnormally aggressive or seriously irresponsible conduct. In most circumstances, observed cessation of key behaviours, or clinically significant reductions in their frequency, will provide adequate evidence of change. In evaluating this, however, account must be taken of the extent to which characteristics of detention or a treatment regime are serving to render the problematical conduct temporarily impossible of execution. There may be similar difficulty in deciding whether infrequently occurring irresponsible conduct of extreme severity has ceased. Judgement in these circumstances is likely to be most readily optimised by drawing upon clinical experience of similar profiles.

2.2 CRIMINAL JUSTICE SYSTEM[42]

There are a number of Statutes that are specifically relevant to people with learning disabilities, and for which psychological assessment and opinion may have some applicability. The following is not intended as an exhaustive list, but does include some legislative areas in which a psychologist's opinion or advice may be sought (see also Appendix II):

- **Sexual Offences Act 1956**[43] – includes reference to unlawful (i.e. outside marriage) sexual intercourse with a woman who is a *'defective'*, and reference to indecent assault on a man or woman who is a *'defective'*.
- **Mental Health Act 1959** – Section 128 deals with unlawful sexual intercourse between a male employee and a woman being treated for *'mental disorder'*. The Act defines *'mental disorder'*.
- **Sexual Offences Act 1967** – deals with male homosexuality, and includes reference to males with *'severe mental handicap'*.
- **Mental Health (Amendment) Act 1982** – updated parts of the Sexual Offences Acts 1956 and 1967, amended the definition of *'defective'* and *'severe mental handicap'*.
- **Police and Criminal Evidence Act 1984 (PACE) and the Codes of Practice** – concerning the requirement for an *'appropriate adult'* to be present at interviews related to suspects who have a *'mental handicap'*.
- **Mental Health (Scotland) Act 1984** – Section 106 relates to unlawful sexual intercourse with a woman who has a *'mental handicap'*.[44]
- **Mental Health (Scotland) Act 1984** – Section 107 relates to unlawful sexual intercourse between a male employee and a woman being treated for *'mental disorder*'.

Again, it is important to re-emphasise that clinical diagnoses / classifications are not the same as *legal* classifications. Gunn (1996) notes: *'It is important to understand the definitions used in each Act and to remember that these terms have a specific legal meaning which may not be the same as the meanings given to them in general or professional conversation.'*[45]

However, within a legal context, clinical terminology may justifiably be used to assist the Court to make a judgement, with respect to legal classifications. The relationship between the clinical and the legal context has to be carefully considered. For instance, in drawing conclusions from one legal case, Gudjonsson and Haward (1998) note that *'… successful submissions under PACE might involve borderline IQ scores'*, i.e. IQ scores of 70 to 79 (Wechsler, 1981). In the same case, trial judges were *'… not attracted to the concept that the judicial approach to submissions under… the Police and Criminal Evidence Act 1984 (PACE) should be governed by which side of an arbitrary line, whether 69/70 or elsewhere, the IQ falls.'* Equally the same authors stress the difficulties of generalising, even within the legal system, noting a case in which *'the Court of Appeal decided it was wrong to take the IQ scores from one case and apply them slavishly to another.'*

[42] Some legislation across England and Wales, Scotland and Northern Ireland will differ.

[43] An 'unlawful sexual intercourse' clause appears, in Scotland, in the Mental Health (Scotland) Act 1984. [s.106] However, it is important to note that the *level* of disability criterion differs.

[44] This is a similar clause to that in the Sexual Offences Act 1956 under English Law. However, it should be noted, again, that the *level* of disability criterion, under the respective legislation, differs.

[45] Gunn (1996) cites a case in which the Court of Appeal decided that the words defining 'defective' were *'words of the ordinary English language'* and that whether someone is a 'defective' is to be measured by the *'standards of normal persons'* and is to be decided by the jury.

Finally, it is important to note that although, within English law, individuals identified as 'defective'/'severely mentally handicapped' within the Sexual Offences legislation are considered, in law, as not being able to consent to unlawful sexual relationships,[46] this should not be used as a generalised criterion for determining the ability to consent with respect to other issues, choices or situations. Again, any assessment addressing mental incapacity/capacity and issues of consent should not rely on generalised inferences relating to broad classification but should be conducted in the context of the particular issues in question and of the individual being assessed.[47]

2.3 LOCAL GOVERNMENT/BENEFITS LEGISLATION

Classifications that are relevant to people with learning disabilities appear in local government/benefits legislation. Examples of associated definitions are given in Appendix II.

Benefits legislation is quite complex, and subject to frequent change, so in those instances when an opinion of a psychologist is sought, the psychologist should be fully aware of the context of the assessment, and of any recent changes within the legislation. It should also be noted that interpretations of the Regulations are subject to Commissioners' decisions. As within the criminal justice system, the clinical diagnoses/classifications are not the same as the classifications within the specific Act/Regulation' the latter will have their specific own meanings.[48]

However, again, as within the criminal justice system, an expert opinion may be requested in order to make a judgement in any one particular case.

2.4 MISCELLANEOUS

Classifications with respect to people with learning disabilities occur in a variety of other contexts. Examples of associated definitions are given in Appendix II.

[46] Again, it should be noted that the *level* of disability criterion differs for Scotland. See the Mental Health (Scotland) Act 1984 (s. 106). See also McKay (1994).

[47] For further discussion on issues of incapacity and consent see Wong, J. (1997); British Medical Association and the Law Society (1995); Law Commission (1995); Command Papers Cm 3803 (1997) & Cm 4465 (1999).

[48] In the context of the Disability Living Allowance (higher rate mobility component) a Commissioner's decision (CDLA/6219/97) has defined 'severe impairment of intelligence' as an IQ of 55 or less. However, as with other medico-legal judgements, it has also been argued that 'intelligence' is used in the ordinary sense of the word and has no *technical* meaning (Commissioner's decision CDLA/12148/96) (cited in Paterson, 1999). Either way, a judgement should not be based on severe impairment of intelligence alone, but should take into account impairment of social functioning and, in this case, other aspects. The Court of Appeal Judgement – Megarry v CoA gives support for this. Additionally this same judgement (relating to a person with autism) concluded that whilst the claimant's IQ is likely to be *'the essential starting point for considering impairment of intelligence'* and that it was *'reasonable to take an IQ of 55 or less'* as being severe impairment of intelligence, the IQ score would not necessarily prove decisive. Thus (certainly in the case of people with autism), where the IQ is over 55, all the available evidence should be considered when deciding if the severe impairment of intelligence is satisfied.

2.5 'GATE-KEEPING' – ACCESS TO SERVICES

There has been some debate regarding requests for psychological assessment which relate to a person's suitability or eligibility for access to learning disability services (i.e. a 'gate-keeping' function). Although the Society cannot be prescriptive regarding local responses, it is important to note that access to services will not depend solely on the characteristics of the individual service user but also on the extent and configuration of local service provision.[49]

It is important to recognise that whilst some of these requests may be presented in terms of *assisting access* to specialist services, this may also imply *restricted* access to or *exclusion* from appropriate generic / mainstream services. Psychologists should be aware of this risk and should avoid making a recommendation that, by implication or inference, might be used to restrict or exclude people from the most appropriate services available.

In responding to requests to classify people for service / administrative purposes, there is a danger that the unique characteristics of the individual will be lost. In such circumstances it is essential not simply to apply labels, but to focus the assessment on specific individual need, and to make recommendations on the type of service and supports that would best meet that need.[50,51,52]

[49] Fox & Lamb (1998) have invited comments on the use of psychological assessments for potential administrative service functions. This issue has been considered by a number of clinical psychologists on behalf of local services e.g. Burton (1997), Dodd & Webb (1998) and Evers & Hill (1999).

[50] Within some areas, people with a learning disability receive high quality psychological primary care services like any other person. Unfortunately, however, there is also evidence that people with a learning disability may be marginalised, having little access to mainstream services (DoH, 1998; Band, 1998).

[51] The AAMR (1992) avoids sub-classification, and emphasises a process which relates a person's needs with respect to '*… the intensities of supports necessary to enhance the person's independence/interdependence, productivity, and community integration*.'

[52] Schalock *et al.* (1994).

Part 3: Appendices

APPENDIX I: CLINICAL DEFINITIONS

Organisation	Terminology	Definition/Criteria
ICD-10[53] The ICD-10 Classification of Mental and Behavioural Disorders[54]	Mental Retardation	*… a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities.* *… Adaptive behaviour is always impaired …*
AAMR The American Association on Mental Retardation (1992)	Mental Retardation	*… substantial limitations in present functioning. It is characterised by significantly sub average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home-living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age 18.*
DSM-IV Diagnostic and Statistical Manual of Mental Disorders[55]	Mental Retardation	*(a) Significantly sub-average intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test.* *(b) Concurrent deficits or impairments in present adaptive functioning (i.e. the person's effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home-living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety.* *(c) The onset is before age 18 years.*
Department of Health (1998)[56]	Learning Disability	*... usually described as a significant impairment of intelligence and social functioning acquired before adulthood.*

[53] At the time of writing, *The International Classification of Impairments, Activities and Participation: a Manual of Dimensions of Disablement and Functioning* ICIDH-20 is being developed. The intellectual disability part of this manual is being trialed in Australia (Cooper, 1997).

[54] World Health Organisation (1992).

[55] American Psychiatric Association (1994).

[56] Department of Health (1998): *Signposts for Success…*

APPENDIX II: SAMPLE OF RELATED DEFINITIONS

MENTAL HEALTH LEGISLATION

Act/Regulation	Terminology	Definition/Criteria
Mental Health Act 1983	Mental Disorder	*Mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of mind.*
	Arrested or incomplete development of mind	Not defined.
	Mental Impairment	*A state of arrested or incomplete development of mind … which includes significant impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned.*
	Severe Mental Impairment	*A state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned.*
Mental Health (Scotland) Act 1984	Mental Disorder	*Mental illness or mental handicap however caused or manifested.*
	Mental Impairment / Severe Mental Impairment	As for Mental Health Act 1983.
	Mental Handicap	*A state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning.*
	Mental Disorder	*Mental illness, mental handicap and any other disorder or disability of mind.*
Mental Health (N.Ireland) Order 1986	Mental Handicap	*A state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning.*
	Severe Mental Handicap	*A state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning.*
	Severe Mental Impairment	*A state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned.*

LOCAL GOVERNMENT/BENEFITS LEGISLATION

Act/Regulation	Terminology	Definition/Criteria
Local Government Finance Act 1992 (Relates to Council Tax)	Severely Mentally Impaired	*Severe impairment of intelligence and social functioning (however caused) which appears to be permanent. This includes people who are severely mentally impaired as a result of a degenerative brain disorder such as Alzheimer's Disease, a stroke or other forms of dementia.*
Social Security (Disability Living Allowance) Regulations 1991; **Social Security Contributions and Benefits Act 1992 sec. 73** (Relates to the higher rate mobility component of the Disability Living Allowance)	Severely Mentally Impaired	*A state of arrested development or incomplete physical development of the brain, which results in severe impairment of intelligence and social functioning.*[57] *'Arrested development or incomplete physical development of the brain' must take place before the brain is fully developed. In most cases this will be by the late twenties, and invariably before age 30. (R(DLA)2/96).* Note: Degenerative diseases such as Alzheimer's Disease that begin after the brain is fully developed do not satisfy the severely mentally impaired criteria. Criteria for higher rate mobility component of Disability Living Allowance includes a *'severe behavioural problem'* criteria which includes *(extreme) disruptive behaviour … regularly requires another person to intervene and physically restrain … so unpredictable that another person [must] be present and watching over him whenever he is awake. Reg 12(5), (6) DLA Regs.*
Social Security (Incapacity for Work) General Regulations 1995; Social Security (Incapacity Benefit) (Transitional) Regulations 1995	Severe Learning Disability	*A condition which results from the arrested or incomplete physical development of the brain, or severe damage to the brain, and which involves severe impairment of intelligence and social functioning.* (This is less restrictive than 'severely mentally impaired' as defined in some Regulations in that it includes conditions that arise later in life, e.g. a later head injury.)
Disability Discrimination Act 1995	Disability	*A physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities. 'Mental impairment' includes learning disabilities and mental illness (if recognised by a respected body of medical opinion).*

[57] For further discussion, see footnote 48, page 18.

CRIMINAL JUSTICE SYSTEM[58]

Act/Regulation	Terminology	Definition/Criteria
Police and Criminal Evidence Act 1984; Police and Criminal Evidence (N.Ireland) Order 1989	Mentally Handicapped (person)	*A state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning.*
Sexual Offences Act 1956	Defective	*A state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning.* [As amended by the Mental Health (Amendment) Act 1982].
Sexual Offences Act 1967	Severe Mental Handicap (males)	*A state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning.* [As amended by the Mental Health (Amendment) Act 1982].

MISCELLANEOUS

Act/Regulation	Terminology	Definition/Criteria
Registered Homes Act 1984	Mental Handicap	*A state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning.*
Residential Care Homes Regulations 1984	Mental Handicap	*A state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning.*
Road Traffic Act 1988	Mild to Moderate Mental Handicap	*If stable, it may be possible to hold a licence but he/she will need to demonstrate functional ability at the wheel and be otherwise stable [No other definition is given].*
	Severe Mental Handicap	*A state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning.*

[58] The section refers to legislation in England and Wales. Although comparable legislation in Scotland may exist, this may appear in different Statues. The difference in the level of disability criterion for unlawful sexual intercourse between Sexual Offences Act 1956 [England] and Mental Health (Scotland) Act 1984 (s. 106) is particularly important. A useful reference on Scottish law relevant to personal relationships is McKay (1994).

APPENDIX III: CONFIDENCE LIMITS IN PSYCHOMETRIC ASSESSMENT

Confidence intervals for any score can be calculated from the standard error of measurement (SEM) statistic. This indicates the probable extent of error in any score in the set to which it applies. The range of error depends on test reliability, so the higher the reliability, the narrower the range of error. Most test manuals should provide either the SEM statistic directly or, at the very least, reliability figures from which it can be calculated. Where such information is not available for a particular test, the use of results from that test is severely constrained.

If a particular test does provide this statistic, it is possible to derive the 95 per cent probability of the limits (i.e. the confidence limits) within which a particular score might be expected to lie. Assuming that the test has been standardised on a large sample, this can be done by multiplying the SEM by 1.96.

The WAIS-R (Wechsler, 1981), which can be used with persons over 16 years of age, gives SEM figures for IQ scores which vary depending on the age group concerned. For *Full Scale* IQ scores, SEM figures range from 2.20 to 2.96, with an average of 2.53.[59] This latter figure gives confidence limits of ± 4.96 (i.e. approximately ± 5).

The WAIS-III^{UK} (Wechsler, 1999) provides 90 per cent and 95 per cent confidence intervals for each level of observed score for IQ and Index scores. These have been calculated slightly differently – being based on the estimated true score and standard error of estimation for each observed score level.

Figures for other tests will obviously vary and it should be noted that, as a general rule, intelligence tests are least reliable at their extremes, and the SEM figures published in the test manuals may contain an underestimate of the size of measurement error in the case of those with greater intellectual disability.

At transition points of classification (e.g. between significant and severe impairment of intellectual functioning) it will be necessary to treat IQ figures with caution. To make allowance for the possibility of measurement error, the limits within which the IQ score probably lies should be stated. The chartered psychologist will be guided by proper use of psychometric information in determining whether or not a particular individual is functioning above, at, or below a given transition point.

There has been some debate about the interpretation of scores around the transition points for the age bands of particular tests (Murray & McKenzie, 1999).[60] Some caution is needed when the age of the person being assessed is close to the age transition points.

[59] Figures for Verbal IQ and Performance IQ differ.

[60] See also Collerton (1999) and Leyin (2000).

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Afterword

From the presented discussions on the definitions of learning disabilities – and of the rather formal contexts in which they may occur – it is important, as stated in the Introduction to this document, that the reader does not to infer that psychometric testing is sufficient, or always necessary, to produce a meaningful assessment of a person with learning disability. Indeed without a broader framework, any assessment based solely on psychometric assessment – and any resultant classification – would miss many important aspects of the person who is being assessed. This general view cannot, perhaps, be expressed more eloquently than by the sentiment expressed in the following:

Rebecca

'When I first saw her – clumsy, uncouth, all-of-a-fumble – I saw her merely, or wholly, as a casualty, a broken creature, whose neurological impairments I could pick out and dissect with precision: a multitude of apraxias and agnosias, a mass of sensorimotor impairments and breakdowns, limitations of intellectual schemata and concepts similar to those of a child of eight. A poor thing, I said to myself …

'The next time I saw her, it was all very different. I didn't have her in a test situation, 'evaluating' her in a clinic. I wandered outside, it was a lovely spring day, with a few minutes in hand before the clinic started, and there I saw Rebecca sitting on a bench, gazing at the April foliage quietly, with obvious delight. Her posture had none of the clumsiness which had so impressed me before. Sitting there, in a light dress, her face calm and slightly smiling, she suddenly brought to mind one of Chekov's young women – seen against the backdrop of a Chekovian cherry orchard. She could have been any young woman enjoying a beautiful spring day. This was my human, as opposed to my neurological, vision …

'As I approached, she heard my footsteps and turned, gave me a broad smile, and wordlessly gestured. 'Look at the world', she seemed to say. 'How beautiful it is' …

'She had done appallingly in the testing – which, in a sense, was designed, like all neurological and psychological testing, not merely to uncover, to bring out deficits, but to decompose her into functions and deficits. She had come apart, horribly, in formal testing, but now she was mysteriously 'together' and composed.'

Sacks, O. (1985)

Rebecca in *The Man who Mistook his Wife for a Hat.*

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The British Psychological Society

Challenging Behaviours

Psychological interventions for severely challenging behaviours shown by people with learning disabilities

Clinical Practice Guidelines

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Preface

I am delighted to write a foreword for these guidelines regarding interventions for severely challenging behaviour shown by people with learning disabilities. Challenging behaviour, in the wide range of ways in which it presents to families, care staff, and not least to other people with learning disabilities, may be threatening, or may lead to actual assault. Any well formulated guidance that helps to minimise the probability of such behaviour, and thereby to increase the likelihood that the person showing the behaviour will be more able to be accepted and included in a fuller range of social activity, is welcome.

The guidelines are very carefully constructed to follow the path from first presentation of a behavioural problem, through to evaluating the outcome of an intervention. They include both core guidance for a wide range of people to use, and more detailed guidance for specialist staff working with people with learning disabilities. They are based on a thorough review of the most relevant literature. Perhaps most importantly of all, they have been developed by psychologists with a thorough understanding of the day-to-day realities of working with people with challenging behaviour.

A wide range of clinical practice guidelines is now being produced by a range of statutory and professional bodies. These guidelines take their place alongside other guidelines developed by clinical and other applied psychologists that can be used by members of other professions, and to guide other workers in the field. They also contain useful information that is applicable to those other fields of practice where severely challenging behaviour may be displayed, such as people with behavioural difficulties arising from an acquired brain injury, or from serious mental disorder.

The best recommendation for these guidelines will be that they are widely used by a range of people in a range of settings. I commend the authors for designing them for that purpose, and hope that they will become a gold standard for work in this field.

Professor John Hall FBPsS

Chair, QUEST (The Quality and Clinical Effectiveness Sub-committee of the Division of Clinical Psychology of the British Psychological Society

Executive summary

These Clinical Practice Guidelines have been prepared for clinical psychologists who provide psychological interventions to people with learning disabilities who also display behaviours that severely challenge services. They have been prepared by a small group of experienced clinical psychologists following a process that has included a detailed review of the relevant literature, a conference of clinicians, advice from acknowledged experts in the field, and an extensive consultation process within the profession.

This area was selected for guidelines development on account of the level of clinical need, the existence of an evidence-base, the potential contribution of clinical psychologists to this group of people, and the potentially serious consequences for people when services do not respond appropriately to their challenging behaviour.

Currently there are only a limited number of well-designed randomised controlled trials in this area, and many of the guidelines are based on case controlled studies and clinical consensus. Bearing this in mind, the guidelines make a distinction between 'good' practice and 'essential' practice, with the majority of the recommended practices falling into 'good' practice. There is therefore an emphasis in the language of the document, on 'should' and 'ought', with only a minority of the guidelines using 'must' to describe essential practice. It is the intention of the authors that the guidelines will be used in local services and by individual psychologists. They will need to be adapted for local use, especially where local policies and procedures are already available covering key aspects of the guidelines.

The guidelines lean heavily on the literature contained within the applied behaviour analysis field. This reflects the current state of research in this area. However, it is emphasised that the guidelines are applicable to psychologists from any theoretical or philosophical background.

The guidelines recommend a process that is a) person centred; b) takes account of the three elements- the person, their environment and their behaviour and the interaction between them; and c) adopts a series of stages that include:

1. Pre-assessment
Preliminary information gathering in order to identify risk and priorities, and hence to shape the initial focus of a psychological assessment.

2. Assessment
Structured and systematic gathering of information concerning the person, the social, interpersonal and physical environment and the behaviour which is challenging.

3. Formulation
The integration of the assessment information into a hypothesis that can lead to an appropriate intervention plan and means of evaluating the accuracy of the hypothesis.

4. Intervention
An intervention for working with people who present extreme challenges that is likely to include: a) reactive behaviour management strategies that aim to contain the behaviour which presents a risk of harm or injury while; b) proactive intervention and treatment strategies are implemented through planned interventions.

5. Evaluation
Measures of change are required in order to determine the impact or effectiveness of the selected interventions.

6. Feedback
Information about the process of intervention and its effectiveness will need to be communicated to all relevant parties.

1. Introduction

These guidelines have been developed by a group of clinical psychologists who work with people who have learning disabilities (Tina Ball, Alick Bush and Eric Emerson). The basis of the guidelines has been a detailed review of the relevant literature, which provided an extensive evidence base. This process was supported by a wide reference group of experts in the field and a conference of specialist psychologists that was convened specifically to look at what constitutes current good practice in this area.

Draft guidelines were presented at the annual national conference of the Learning Disabilities Special Interest Group (now the Learning Disabilities Faculty) of the British Psychological Society's Division of Clinical Psychology (DCP) and circulated for comment within the profession. This consultation led to an amended version being submitted for peer review through the British Psychological Society Centre for Clinical Outcomes Research and Effectiveness and for circulation as a draft document. The guidelines were further updated in 2002, following a second review of the literature.

During this process, contributions have been made to key sections of the guidelines by acknowledged experts in the relevant areas. We are grateful to David Allen, Nigel Beail, David Felce, Sara Fovargue, Ian Gray, John Hall, Theresa Joyce, Glynis Murphy, Janet Robertson and Peter Wheeler. Funding and moral support for the development of the guidelines have been provided by the British Psychological Society (BPS) through the Quality and Effectiveness Subcommittee (QUEST), the Service Development Subcommittee, and the Faculty for Learning Disabilities. Colleagues in the Trent Region Faculty for Learning Disabilities have been interested and helpful throughout the process of guideline development. We would also like to acknowledge the support of colleagues in Sheffield Care Trust (previously Community Health Sheffield NHS Trust), particularly the Clinical Effectiveness Department and Psychological Health Sheffield for their flexible and practical help.

The development of the guidelines has only been possible with the input of numerous contributors. There are too many to name everyone individually, but particular mention must be made of Karen Moore (who carried out the initial literature search), Martin Burke, Sarah Heke and Linda Lambert (who made the conference possible), Clare Burnell (who carried out detailed critiques of various drafts from very different perspectives), Katia Allchurch (who organised the final draft), Fiona MacDonald, Anna Mitchell, Sophie Heason and Karen Bartle.

These are national guidelines for clinical psychologists which will need to be adapted to local conditions. It is anticipated that local groups of psychologists will use them as a framework for developing more detailed guidelines for their own work, to inform clinical audit and the training of clinical psychologists.

Other professionals, service providers and purchasers may find them helpful in clarifying what to expect from clinical psychology and what constitutes good practice. They are not intended to advise other professionals on their practice.

We believe that psychologists have a particular role to play in working with people whose behaviour is challenging. Challenging behaviour is in itself a psychological concept, and interventions derived from psychological principles have been demonstrated to be the most effective over a number of years.[1] It is our responsibility as a profession to ensure that people with learning disabilities, their families and carers can have access to the most effective remedies for psychological distress and behaviour which is disturbing.

Although these guidelines have been derived specifically for psychologists, this is not meant to imply that only psychologists can or should provide a service for people who challenge. Good practice must be multidisciplinary and draw on the skills of the full range of clinicians. It is also absolutely essential that psychologists work in close partnership with people with learning disabilities who show challenging behaviour, and their families and carers.

These guidelines need to be read within the context of *Valuing People: A New Strategy for Learning Disabilities for the*

21st century (2001).[2] This White Paper sets out how the UK Government intends to provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities. There is a requirement to *'ensure that all agencies commission and provide high quality, evidence-based and continuously improving services which promote both good outcomes and best value'* (p.90).

The White Paper recognises that commissioning and providing services for people who present significant challenges is one of the major issues facing learning disability services. Learning Disability Partnership Boards are directed to 'ensure that local services develop the competencies needed to provide treatment and support within the local area.' (p.103). These guidelines may help to achieve this.

Within Scotland, a review of services for people with learning disabilities *(The Same As You?)*[3] conducted by the Scottish Executive, outlines a vision for modernising community care, including the provision of specialist support to people who challenge services.

The guidelines have largely been prepared within a policy context relating to adults who have learning disabilities. However, the clinical evidence-base generally relates to both children and adults, and except where indicated, the guidelines should be interpreted as applying to psychologists who work with either children or adults. Psychologists who work with children are directed to the forthcoming Children's National Service Framework and the website[4] that provides emerging findings from the NSF.

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[2] See DoH website at www.doh.gov.uk/vpst/papers.htm

[3] See the Scottish Exeutive website at www.scotland.gov.uk/ldsr/default. Asp

[4] See the DOH website at www.doh.gov.uk/nsf/children.htm

2. Development of the guidelines

2.1 The need to develop guidelines

The area of challenging behaviour shown by people with learning disabilities was recognised as a clear priority for the development of clinical practice guidelines by the British Psychological Society when it agreed to fund this project. There are three major reasons for this:

1. clinical need;
2. the presence of a strong evidence base describing successful interventions;
3. problems with the successful application of effective interventions.

2.1.1 Clinical need

Challenging behaviour is an area of immense clinical need. It can directly cause pain, injury and distress to people with learning disabilities, their families and care staff and other professionals working with the people concerned.

The consequences can include physical injury and even death as a result of self-injury,[5] injury to others,[6] distress to families,[7 8] and stress to care staff.[9 10]

The occurrence of such behaviour leads to people being the last to leave inappropriate hospital accommodation and the first to return to it, often out of district and at considerable expense.[11] Parents are more likely to look for residential care if their sons or daughters are challenging.[12] People whose behaviour is challenging are at greater risk of abuse[13] and of living in deprived and damaging environments.[14] People who are challenging are more likely to be medicated [15 16 17] or physically restrained[18] or to be subject to abusive techniques in the name of 'behavioural interventions' such as being spanked, pinched, suddenly shouted at or being given painful electric shocks.[19 20]

Challenging behaviour is relatively common among people with learning disabilities. Numerous prevalence studies have been undertaken in the UK. Stress has been placed on the importance of social processes in leading to particular behaviours being seen as challenging. One implication of this approach is that attempts to measure the prevalence of challenging behaviour are themselves bound by social processes. Estimates of the prevalence of challenging behaviour are influenced by such factors as: (1) the constraints and expectations of particular contexts and cultures which combine to define particular behaviours as challenging; and (2) methodological factors such as the selection of operational definitions, methods of case identification (e.g. review of case notes vs. interview with care staff) and the overall sampling strategy adopted within the study (e.g. total administratively defined population of people with intellectual disabilities, children with intellectual disabilities at school). Nevertheless, UK studies suggest that between 5 and 15 per cent of all people with learning disabilities who are known to services show behaviours which present significant challenges to carers.[21 22 23 24 25] Similar prevalence rates have been reported in North America.[26]

Qureshi, Kiernan and colleagues[24] conducted a survey in 1987 in seven administrative areas in the North West of England with a total (general) population of 1.54 million. They screened approximately 4200 people with learning disabilities and identified people as showing serious challenging behaviours if they had either:

- at some time caused more than minor injury to themselves or others, or destroyed their immediate living or working environment; or
- showed behaviours at least once a week that required the intervention of more than one member of staff to control, or placed them in danger, or caused damage which could not be rectified by care staff, or caused more than one hour's disruption; or
- showed behaviours at least daily that caused more than a few minutes disruption.

Using this definition, 1.91 people per 10,000 of the general population (range 1.41 to 2.55 per 10,000 across the seven areas) were identified as having learning disabilities and serious challenging behaviour. This translates to an estimated prevalence rate of 7 per cent of all people within these areas who had been administratively defined as having learning disabilities. In a follow up study, Emerson *et al* (2001)[27] repeated the procedures used in

the 1987 study in two of the original areas (total population, 0.47 million). Using a slightly amended definition of 'serious', they reported overall prevalence rates of 3.62 people per 10,000 of the general population as having learning disabilities and serious challenging behaviour (equivalent to 8 per cent of the people with intellectual disabilities who were screened). Combining the results of these studies gives an overall prevalence for serious challenging behaviour of 2.40 per 10,000 of the general population or 7.3 per cent of people administratively defined as having learning disabilities.

People who show one kind of challenging behaviour are likely to show other kinds as well.[27 28 29 30 31 32] For example, people who self-injure are likely to engage in more than one type of self-injurious behaviour. Oliver *et al.*[29] found 54 per cent of their population showed two or more types of self-injurious behaviour. Murphy *et al.* (1993),[30] in a study of people whose self-injury was severe enough for them to be given protective devices, found that 40 per cent were also physically aggressive and 36 per cent were destructive to property. A sizeable minority of people with learning disabilities therefore show severe and multiple forms of challenging behaviour.

2.1.2 Evidence base demonstrating successful interventions

Extensive literature searches and meta-analyses[33 34] have demonstrated that interventions which are based on psychological principles derived from learning theory, are currently the most effective interventions for reducing the incidence of challenging behaviour in people with learning disabilities. The meta-analysis by Didden[33] and colleagues in particular, argues that the literature demonstrates a convincing level of change in terms of reducing challenging behaviour through the use of systematically applied behavioural approaches. The impact is much more effective than that demonstrated by medication, for example.[35]

There is some evidence to support the effectiveness of cognitive behavioural interventions for the management of anger and impulsiveness in people with learning disabilities who have the motivation and the cognitive and communication skills to use such approaches.[35]

There are also a few studies which indicate that changes to the service environment can reduce the incidence of challenging behaviour in that setting.[36]

2.1.3 Problems with the application of effective interventions

The application of these techniques in everyday clinical practice and as reported in the literature is neither as systematic nor as effective as might be hoped. The majority of people whether in institutions, in the community or at home with their families are not receiving any effective psychological interventions for their challenging behaviour.[37 38 39]

A related problem is that punitive and aversive techniques of behavioural control have been misused with people with learning disabilities. Attempts are still made to justify bad practice and abuse by calling it a 'behavioural programme'.

Clements[40] has suggested that one reason for the failure to use applied behavioural techniques of demonstrable effectiveness is that the scientific approach lost favour among some psychologists because of its identification with a narrow behaviourism which was 'cold, mechanistic, manipulative and non-humanistic'. Certainly some of the older studies of interventions for challenging behaviour are aversive to read because of their apparent lack of empathy with the 'subjects', but in more recent work in the applied behavioural tradition, humanity and creativity are very evident.[41] Clements argues against a narrow view and urges the reapplication of mainstream psychological thinking to work with people who challenge services. Mainstream psychological thinking would of course include thinking about cognitions, emotions and organisations, for example, as well as behaviour.

Another possible reason suggested by colleagues during the consultation period for these guidelines was that effective work was intensive and time consuming. Many clinical psychologists feel under pressure to work rapidly and see large numbers of people to maintain high activity counts. Challenging behaviour creates its own pressures too – the severity of the problem can lead to a need for interventions to be in place rapidly. But speed of response and the need to work with as many people as possible should not be at the cost of being effective. Applied behavioural approaches – functional analysis, setting up and evaluating appropriate interventions – are time-consuming but clinically effective. The other approaches for which there is some evidence of effectiveness in reducing challenging behaviour – cognitive behavioural interventions

and organisational change – also take time to be carried out effectively. Perhaps psychologists need to develop more confidence in the effectiveness of what they do so that they can invest the time that is necessary to be effective.

A third possible reason is that the work is difficult and involves spending time with people who are challenging to psychologists as well as to services, and with groups of staff who may be demoralised and demotivated. As well as the evidence demonstrating the effectiveness of psychological interventions for challenging behaviour, there is also a literature which shows the persistence of many challenging behaviours.[42] [43] We need to look to support and development systems for psychologists, and how we motivate ourselves as well as others to persist with difficult and enduring problems.

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3. Definitions

3.1 Learning disability

People with learning disabilities do not constitute an homogeneous group. However, in terms of diagnosis and classification there are a number of features of learning disability which have gained widespread acceptance across professional boundaries within the UK and America. Irrespective of the precise terminology, or the wording in the various definitions, there are three core criteria for learning disability:[44]

- significant impairment of intellectual functioning;
- significant impairment of adaptive/social functioning;
- age of onset before adulthood.

This definition is consistent with the ones provided in the *Valuing People* White Paper,[45] American Association on Mental Retardation,[46] ICD-10 (World Health Organisation),[47] DSM-IV (American Psychiatric Association)[48] and Department of Health.[49]

The term 'learning disabilities' is not being used in these guidelines for people with specific areas of learning difficulty (e.g. dyslexia) who do not meet the criteria above.

3.2 Challenging behaviour

The definition of challenging behaviour most commonly used in services is:

Severely challenging behaviour refers to behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities (Emerson *et al*., 1988).[50]

The behaviour needs to be seen as abnormal in the context of the person's culture.

Felce and Emerson[51] elaborated on this definition in 1996 when they said:

One of the reasons for the adoption of the term 'challenging behaviour' was to provide a reminder that severely problematic or socially unacceptable behaviour should be seen as a challenge to services rather than a manifestation of psychopathological processes. In order to respond to this challenge services need to promote positive behavioural development, reduce the occurrence of damaging behaviour and maintain people's access to a decent quality of life despite continuing behavioural difficulties

The usual definition of challenging behaviour raises as many questions about the design and flexibility of support services as it does about people with learning disabilities themselves. There is also the concern that the people who challenge should be seen in terms of their strengths, skills, development and quality of life as well as their challenging behaviour.

Any review of the literature on challenging behaviour demonstrates how broadly the term can be used. The database developed by Didden[52] and his colleagues lists over 50 different behaviours, ranging from adipsia to vomiting. Many authors have dealt with the problem of definition by concentrating on a particular sub group of behaviours, such as self injury or aggression.[53] [54] But prevalence studies that have looked at a wide range of challenging behaviours have indicated that such behaviours often coexist.[55] [56] [57]

As already discussed in Section 2.1.1, one approach has been to define the behaviour in a more precise operational way. Hazel Qureshi, for example, in her survey of the incidence of challenging behaviour in the North West of England defined people as showing challenging behaviour if they:

- Had at some time caused more than minor injuries to themselves or others or destroyed their immediate living or working environment; or
- Showed behaviours at least once a week that required the intervention of more than one member of staff to control, or placed them in physical danger, or caused damage which could not be rectified by care staff, or caused more than one hour's disruption; or

- Showed behaviours at least daily that caused more than a few minutes disruption.[55]

This was revised in follow-up studies, when Emerson and his colleagues defined people with 'more demanding challenging behaviour' as meeting at least one of four criteria:

- they showed challenging behaviour at least once a day;
- their challenging behaviour usually prevented the person from taking part in programmes or activities appropriate to their level of ability;
- their challenging behaviour usually required physical intervention by one or more members of staff;
- their challenging behaviour usually led to major injury (i.e. injury requiring hospital treatment) to either the person themselves, carers or other people with learning disabilities.[58]

Clements[59] has suggested that behaviour should be identified as 'problematic' if it meets two of the following three criteria. The behaviour should be:

- unacceptable by the social standards relevant to the person's age, class and cultural background;
- imposing (or threatening to impose) a significant cost on the person himself (e.g. physical damage, social rejection, limiting opportunities for learning);
- imposing (or threatening to impose) a significant and unreasonable cost on the lives of others.

Other more qualitative researchers have asked parents or care staff to identify what is challenging or problematic for them and worked from that basis, building up a shared understanding of what is challenging behaviour. Hastings[60] showed that care staff he interviewed defined challenging behaviour in a variety of ways:

- challenging/difficult for others;
- not the norm/not acceptable;
- extreme reaction to 'normal' events;
- defined by examples;
- to be controlled/changed.

His work is illuminating for its consideration of how staff beliefs can affect their actions in containing or working with challenging behaviours.

'Challenging behaviour' is a term that has been widely adopted since its first introduction to the United Kingdom in 1987. This may be partly because of the ever-present wish to provide new euphemisms for disturbing experiences.[61] However, it seems to be a useful concept to many people providing services for people with learning disabilities because of the emphasis it places on the social and interactive nature of such behaviours. There is a risk that this emphasis can be lost if it subsumed under more biological based headings such as 'mental health' as in the NHS Executive paper *Signposts for Success*.[62]
Some psychologists have argued that an excessive focus on the challenging behaviour can divert attention away from important issues of how people with learning disabilities can be supported to live full and valued lives. These guidelines will indicate that priority must be given to helping people with learning disabilities who show challenging behaviours to learn new skills, participate in their communities and reach their full potential. But we do a disservice to these individuals and to those living with them or caring for them if we do not address the behaviours which can become such an enormous barrier to individual development and result in social exclusion. Fox and Emerson[63] have shown that a range of different stakeholders rate a reduction in the severity of challenging behaviour to be the most important outcome of interventions. The complexity of the definition of challenging behaviour reflects the nature of work with people who are challenging. The definition needs to be both tangible, so that the behaviours can be measured and worked with, and dynamic, so that the social and interactive elements are not lost. The use of the term 'challenging' to describe behaviours is an attempt to make this clear.

3.3 Clinical practice guidelines

Clinical practice guidelines are defined as:

systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.[64]

Guidelines refer specifically to the process of clinical care. They need to be both scientifically valid and relevant to day-to-day practice.[65]

Scientific validity can be measured by the use of a thorough and systematic review of the relevant literature. Some research is of higher quality than others and care needs to be taken that this factor is recognised and taken account of in the literature review. In the development of clinical practice guidelines in the North of England project, for

example,[66] evidence was categorised according to three levels:

Level 1: evidence from well-designed, randomised controlled trials, meta-analyses or systematic reviews;
Level 2 evidence from well-designed cohort or case controlled studies;
Level 3: evidence from uncontrolled studies or clinical consensus.

We have chosen to adopt these same three levels when weighing up the different degrees of evidence to support these guidelines.

Guidelines are seen as an important element of 'clinical governance' in the new NHS (Department of Health, 1998). National guidance on good practice in health services for people with learning disabilities states that:

'Whenever possible interventions and services should be based on evidence of effectiveness. When this is not available a consensus view of good practice is used.'[67]

The National Institute for Clinical Excellence (NICE)[68] was set up as a Special Health Authority for England and Wales in 1999, with a role to provide patients, health providers and the public with authoritative, robust and reliable guidance on current best practice, for a range of procedures and clinical conditions. NICE has not yet commissioned the development of guidelines relating to people with learning disabilities who challenge services. However, a guideline on 'disturbed (violent) behaviour: the short-term management of disturbed (violent) behaviour in adult psychiatric inpatient settings' is due for completion in August 2004. This is likely to have some applicability to psychologists in this field, although adults with learning disabilities are not covered by the guidelines.

Parallel to NICE is the Social Care Institute for Excellence (SCIE)[69] launched in 2001 with a remit to improve quality in social care services across England and Wales. SCIE, with links to the electronic library for social care[70] is in the early stages of developing a range of Best Practice Guides.

Other useful links are the National Electronic Library for Health Website[71] and the Centre for Evidence Based Social Care.[72]

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4. Process of developing the guidelines

The process of developing these guidelines has had five main components:

1. An extensive review of the literature on psychological interventions for challenging behaviour.
2. The organisation of a conference of clinical psychologists working with people with learning disabilities and with an interest in good practice in the field of challenging behaviour, with a view to identifying clinicians' views on good and bad practice.
3. The presentation of draft guidelines at the annual national Special Interest Group (Learning Disabilities) Conference of the British Psychological Society (now the 'Faculty for Learning Disabilities') and subsequent dissemination of the draft guidelines to psychologists working with people with learning disabilities for comments.
4. The revision of the guidelines following comments received.
5. Peer review of the revised guidelines and final amendments.

4.1 Literature review

A key component of the process of developing the guidelines was the systematic literature review of the PsychINFO database (1982 to 2001) and Medline database (1982 to 2001). The review included 'clinical practice guidelines', 'challenging behaviour' and its synonyms and 'psychological interventions' in people with 'learning disabilities'. We have had access to the Problem Behaviour Database designed by Didden, Duker and Korzilius in Holland which holds summaries of 1000 studies from 31 international journals over 25 years (up to 1995). We have been very grateful for the many review articles, edited collections or collections of key articles, and the meta-analyses[73 74] which have made it easier to come to grips with the evidence base of interventions for challenging behaviour, within the resources available to us. We have not been able to go back to all the original material over the last 40 years and re-analyse it in a systematic, weighted way, and so have been dependent on the meta-analyses, reviews and key articles (identified by frequent citation) as the basis of the review.

We have also been interested to see other attempts to provide a systematic framework for looking at psychologists' work in the area of challenging behaviour. There have been many debates about the ethics and effectiveness of behavioural interventions.[75 76 77] Previous attempts have been made to provide systematic statements of acceptable practice in the USA and Australia.[78]

A special edition of the *American Journal on Mental Retardation* describes[79] the development of seven guidelines for the treatment of psychiatric and behavioural problems in mental retardation. They adopted a process of surveying 48 experts on the psychosocial treatment and 45 experts on the medication treatment of mental retardation.

In the British context, Clements[80] suggests five criteria that should be applied to judging a framework to guide interventions for challenging behaviour. Such a framework should include:

- derived from mainstream psychology;
- extensive;
- generative;
- humanistic;
- disseminable.

We have found these suggestions helpful in the development of these guidelines, and have used them as guiding principles.

4.2 Clinical consensus

Relevance to day-to-day practice can be assessed by consulting with clinicians in both formal and informal ways (e.g. by questionnaire, at conferences, by monitoring the implementation of the guidelines). Involving practising clinicians in the development of guidelines has been found to be particularly helpful in ensuring that they are relevant. These guidelines were developed by psychologists working with people with learning disabilities and challenging behaviour, with support and comments from many other practising psychologists. This is similar to the approach used by Rush and Frances.[81]

Academic and clinical experts with experience of working with people who present extreme challenges, were invited to a consensus conference. Various presentations provided an overview of current 'best practice' in the field, and gave an opportunity to check the validity of the information derived from the literature review, against current expert opinion. Identifying clinical consensus has been particularly important in those areas of psychological practice where the literature is least extensive.

Draft guidelines were drawn up, based upon the systematic literature review and consensus conference. These were presented to the Division of Clinical Psychology's Special Interest Group and through circulation within the profession. This generated 30 detailed comments from both individuals and groups of psychologists. Specific comments were sought from acknowledged experts. On the basis of the feedback, the guidelines were redrafted with a further updating of the literature.

The revised guidelines were submitted for peer review by members of the Division of Clinical Psychology of the British Psychological Society through the Service Development subcommittee and the Quality and Effectiveness subcommittee.

4.3 The scope of the guidelines

These guidelines focus specifically on interventions that are designed to provide effective help for people who are challenging. They have been guided to a considerable extent by the published literature, because of a need to be able to evaluate interventions critically and establish whether a particular approach can be replicated. We have not included the more general literature about working effectively with people with learning disabilities as that is beyond the scope of these guidelines. However, we would like to make it very clear that we consider that the literature on creating positive environments and supporting people with learning disabilities in reaching their full potential as members of society must be applied to people who are described as challenging. The guidelines indicate that it is unethical to attempt to prevent challenging behaviours without looking at the social and organisational environments in which they occur, and attending to the individual's needs for growth, development and safety.[82]

Although some of the feedback to us has suggested that these guidelines should be applied only to those psychologists working in the behavioural tradition, this is not our intention. Those of us working on the guidelines come from a variety of therapeutic backgrounds, and are keen that people with learning disabilities should benefit from the full range of psychological interventions available to anyone else in this country. These guidelines are intended to be of use to all clinical psychologists working with people with learning disabilities who present challenges to services.

We would also direct psychologists to the relevant specialist clinical psychology literature for work on mental health and forensic issues. We believe it is important for psychologists working with people with learning disabilities to keep up to date with more general psychological thinking and to seek to apply developments in the mainstream to work with people with learning disabilities.

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5. Ethical, professional and legal context

People with learning disabilities are disempowered and potentially vulnerable to abuse or neglect in our society. Their lack of power reduces their ability to challenge poor practice and restricts their access to redress. Psychologists' professional transactions with this group must therefore be informed by a strong set of ethical standards and values. These values need to be stated clearly, so that they are open to challenge and can be developed further.

The clinicians' conference identified many areas of ethical concern about working with people with challenging behaviours and groups of staff who may feel very challenged. For example, psychologists face ethical dilemmas about whether to continue working in particular settings which they believe may be causing challenging behaviour or be deleterious to the psychological or physical health of staff or people with learning disabilities.[83]

The question of aversiveness – while often simplified by service bans on the use of any aversive procedures – remains a dilemma when both formal and informal interventions are assessed carefully on an individual basis. What is reinforcing for one person (e.g. physical contact) may be highly aversive for another. A programme which is non-aversive in theory (e.g. voluntary time alone 'to calm down') may be aversive in practice (enforced seclusion for someone who enjoys time with staff).[84]

It is essential that ethical considerations as well as the evidence base and clinicians' consensus on good practice inform guidelines in the field of challenging behaviour.

There are four possible components to an ethical framework that can be used to inform psychologists' decision-making about interventions for challenging behaviour:

1. the law – legal requirements, duties and restrictions;
2. professional standards and advice such as the British Psychological Society Code of Practice;
3. local standards, policies and procedures (e.g. Trust statements on use of aversive procedures; local authority adult abuse policies);
4. personal ethical beliefs and principles.

Psychologists need to ensure that they are familiar with the law and local and national policies and procedures, and also that they have the opportunity for expert advice and discussion with experienced colleagues in areas where these more formal sources of guidance are lacking or unclear.

5.1 The Law

Duty of Care

A psychologist, like any other health professional, has a common law duty of care towards people with learning disabilities with whom he or she is working.[85] This means

taking reasonable care to avoid acts or omissions which are likely to cause harm to another person.[86]

Where challenging behaviour is causing harm to the person or others (as is clearly the case with aggressive behaviour or self-injury), it can be argued that the psychologist's duty of care is to intervene as effectively and appropriately as possible. There is no legal guidance as to positive interventions for challenging behaviour – this is a clinical rather than a legal issue – but the law does specify what is unlawful.

Formal and informal interventions run the risk of being against the criminal or civil law if they constitute assault, battery or false imprisonment.[87] *Assault* is when a person is in fear of being attacked by another (e.g. the threatened use of restraint). *Battery* is inflicting unlawful violence on another (e.g. touching, holding, pushing). *False imprisonment* is the unlawful or reckless restraint of victims' freedom of movement (e.g. seclusion or use of a 'time-out' room, preventing someone from leaving a room or building through locks or physical restraints).

The law recognises that there are occasions when actions which may be illegal may be justified if there is an over-riding need to prevent a greater harm, for example, to prevent suicide or to prevent other people being harmed

or to prevent damage to property. People with learning disabilities can be detained lawfully under the Mental Health Act 1983 if they are deemed to have a 'mental disorder'. They may be detained under Section 2 for assessment for a mental disorder. A treatment order (Section 3) requires identification of the disorder as mental illness, mental impairment, severe mental impairment or psychopathic disorder.

Following the Bournewood ruling there is debate about the legality of restricting the movements of people with learning disabilities who can not easily give consent, and are not detained under the Mental Health Act. In the Bournewood issue, patient L was compliant about remaining in hospital, but unable to consent to this, due to incapacity. He was therefore not formally detained but he did not consent to the admission. This deprived him of the rights that detained patients have, to have their detention considered. It is not clear that the Draft Mental Health Bill, 2002, will resolve this, although the Draft Mental Incapacity Bill might be more useful. This case is currently being considered by the European Convention of Human Rights.

Psychologists should ensure that they are aware of the legal status of their clients, in relation to the Mental Health Act (1983) and the new Act when it appears, and also to the Mental Incapacity Bill.

Capacity and consent to treatment

If a patient is touched without their valid consent, the health professional involved may be liable to civil or criminal proceedings. For consent to be valid the person must: i) have the capacity to consent to or refuse the treatment/intervention in question; ii) give their consent voluntarily; and iii) be appropriately informed.[88]

The law is concerned about the ability of people with learning disabilities to consent to treatment, which includes psychological treatment for challenging behaviour. All adults (people over 18 years old) are presumed to be able to consent to treatment[89], but doubts may be raised about the capacity of a person with a learning disability to give consent. To be competent to make their own decisions, patients have to i) be able to take in and retain the treatment information; ii) believe it; and iii) be able to weigh up that information, balancing its risks and benefits.[90] This is a functional approach to the assessment of capacity which means that mental incapacity attaches to specific, thus

a person may be considered capable of making a decision in one set of circumstances (but not in another) and at one point in time (but not at another).[91]

Intellectual ability is not regarded as a good predictor of capacity to treatment,[92] and a psychologist making a decision about someone's capacity to consent to an intervention needs to look at the particular individual and their specific circumstances. The individual's capacity to consent will have to be assessed anew for each occasion as the complexity of the decisions (and the person's capacity) may vary.[87] Furthermore, as the Department of Health has noted:

Care should also be taken not to underestimate the capacity of a patient with a learning disability to understand. Many people with learning disabilities have the capacity to consent if time is spent explaining to the individual the issues in simple language, using visual aids and signing if necessary.[88]

The British Medical Association has recently produced a Consent Tool Kit which suggests that to demonstrate capacity, individuals should be able to:

- understand in simple language what the medical treatment is, its purpose and nature and why it is being proposed;
- understand its principal benefits, risk and alternatives;
- understand in broad terms what will be the consequences of not receiving the proposed treatment;
- retain the information for long enough to make an effective decision; and
- make a free choice (i.e. free from pressure).[93]

These may be useful practical tips in determining capacity; however, it is important to note that these are guidelines and are not legally binding. Thus, the psychologist must ensure that they comply with the *Re C* test.[94]

A joint working party of the BPS, DCP Faculty for Learning Disabilities and Faculty for Older People is developing guidelines on consent for clinical psychologists. In the meantime it would seem appropriate to apply these same criteria to psychological interventions for challenging behaviour. The psychologist has a duty of care which means they may be negligent if they do not provide an

intervention when it is required to preserve the life, health or well-being of the person.

If, following the use of the *Re C* test,[94] it is decided that a person is unable to consent to or refuse treatment, *no one else* can provide consent for that person.[95] The common law doctrine of necessity is used to provide or withhold treatment in this situation, thus health professionals may carry out treatment/interventions which are in the best interests of that patient. Such treatment will be in a person's best interests only if it is carried out to save life, or ensure improvement or prevent deterioration in their physical or mental health. The 'best interests test' dictates that health professionals will not be liable for providing or withholding treatment that they believe to be in the patient's best interests if that belief is supported by a responsible body of medical opinion.[96] No further legal guidance is provided on the 'best interests test'; however, the General Medical Council[97] has suggested that in deciding what may be in the best interests of a patient, account could be taken of:

- options for treatment or investigation which are clinically indicated;
- any evidence of the patient's previously expressed preferences, including an advance statement;
- your own and health care team's knowledge of the patient's background, such as cultural, religious or employment considerations;
- views about the patient's preferences given by a third party who may have other knowledge of the patient, for example the patient's partner, family, carer … or a person with parental responsibility;
- which option least restricts the patient's future choices, where more than one option (including non-treatment) seems reasonable in the patient's best interests.

The British Government has also examined how the best interests of a person should be determined and suggested that the following should be considered:

- the ascertainable past and present wishes and feelings of the person concerned and the factors the person would consider if able to do so;
- the need to permit and encourage the person to participate or improve his or her ability to participate as fully as possible in anything done for and any decision affecting him or her;
- the views of other people whom it is appropriate and practical to consult about the person's wishes and feelings and what would be in his or her best interests;
- whether the purpose for which any action or decision is required can be as effectively achieved in a manner less restrictive of the person's freedom of action;
- whether there is a reasonable expectation of the person recovering capacity to make the decision in the reasonably foreseeable future;
- the need to be satisfied that the wishes of the person without capacity were not the result of undue influence.[98]

Again it is important to note that the GMC guidelines and the suggestions in Making Decisions are *not legally binding*, although they may be of help in practice. Further suggestions are also provided in the BMA *Consent Tool Kit* and *The Lord Chancellor's Department*.[99]

The decision-making process about providing treatment must be carried out in a thoughtful way and the reasons for proceeding with an intervention should be well-documented.[100] Normally, psychologists would be expected to have considered the person's capacity to consent and, if they think the person not able to take a decision, they should ensure that alternatives are discussed in a multidisciplinary meeting, preferably including the person's family, GP, advocate, paid carers and others. As well as 'capacity' for consent to be valid it is necessary to demonstrate that the person gave their consent *voluntarily* and that they were appropriately informed:

Voluntariness – Consent must be freely and voluntarily given, without pressure or undue influence being exerted by partners, family members, or health professionals. The Department of Health notes that there is a potential for the offer of treatment to be perceived as coercion in situations where involuntary detention may be an issue. However, it emphasises that there is a distinction between coercion and reassuring a patient about the benefits of a treatment, but notes that withdrawal of privileges, for example, or using other ways to induce consent is unacceptable and coercion will invalidate the consent.[101]

Information – For consent to be valid, a patient must be informed in broad terms of the nature of the procedure intended.[102] A health professional will be considered negligent if they do not provide information which a responsible body of medical practitioners would provide (the Bolam test – see above).[103] Health professionals

should try and ensure that patients are able to make a balanced judgement on whether to give or refuse consent, but it is advisable to inform the patient of any 'material' or 'significant' risks in the proposed treatment/intervention, any alternatives to it, and the risk incurred by doing nothing. The health professional will normally be responsible for informing a patient of 'a significant risk which would affect the judgement of a reasonable patient'.[104]

Both the GMC and BMA have considered the question of information provision, and have provided extensive guidance, not legally binding, on this issue.[105] [106]

Further guidelines on assessing a person's capacity to consent are presented in Section 9.

Human Rights Act

The Human Rights Act 1998 brings the rights outlined in the European Convention of Human Rights into English Law for the first time. It is designed to protect individuals from abuse by state institutions and people working for these institutions. Several of the articles will have particular relevance to psychologists involved with people who are challenging. These include 'no torture, inhuman or degrading treatment' (article 3), 'the right to liberty and security' (article 5), 'no punishment without law' (article 7). It is likely that the inappropriate use of procedures with people who present challenges, would potentially contravene article 3.

Physical interventions

For the first time, joint guidance on the use of restrictive physical intervention has been prepared by the Department of Health and the Department for Education and Skills.[107] This guidance covers all areas of service that children and adults with learning disabilities and difficulties will use throughout their lives. Physical intervention refers to direct physical contact between one person and another, or to physical contact mediated by an instrument or device. This guidance is specifically concerned with restrictive physical interventions which involve the use of force to restrict movement or mobility or the use of force to disengage from dangerous or harmful physical contact initiated by pupils or service users. The purpose of the Guidance is to ensure that restrictive physical interventions (which employ force) are used as infrequently as possible, that they are used in the best interests of the service user, and that when they are used, everything possible is done to prevent injury and maintain the person's sense of dignity. Restrictive physical intervention should be seen as one part of a broader strategy to address the needs of children and adults whose behaviour poses a serious challenge to services.

The inappropriate use of physical intervention may give rise to criminal charges, action under civil law or prosecution under health and safety legislation. As a general rule, restrictive physical interventions should only be used when other strategies (which do not employ force) have been tried and found to be unsuccessful or, in an emergency, when the risks of not employing a restrictive intervention are outweighed by the risks of using force.

Any restrictive intervention should employ the minimum reasonable degree of force to prevent injury or avert serious damage to property. Its use should be minimised by the adoption of fully documented risk assessment and preventative strategies whenever it is foreseeable that the use of force might be required.

All organisations that provide a service to adults or children with a learning disability or autistic spectrum disorder should have a policy on the use of restrictive physical interventions. Psychologists and others who work with someone when restrictive physical interventions may be utilised, are strongly advised to familiarise themselves with local policies and the Joint Guidance.[108] Other publications that provide advice and guidance on its use should also be referred to.[109] [110] [111]

At present there is clearer guidance on the legal position of children with learning disabilities.[112] The legal situation for adults with learning disabilities is less clear and at the time of writing is under review.[113]

It is particularly important at present for psychologists working with adults to have access to legal and other expert professional advice over difficult cases. The advice of the Official Solicitor can be sought in difficult and complex cases.

Disclosure of an offence by a client

A psychologist may be in the situation of a client disclosing information about an offence. This may occur

when a psychologist is working within a forensic setting or when the client's challenging behaviour includes offending behaviour. This can present the psychologist with a potential dilemma regarding issues of confidentiality. Generally there is no requirement in English law to take steps to prevent a crime. However, in some legislation there are offences concerning such things as 'knowingly suffer'.[114] Additionally there are offences of complicity such as 'accessory' or 'assisting'. Whilst the Sex Offences Act 1956 creates no such offence in relation to the situation described, case law and the 1967 Criminal Law Act may.[115]

Since 1967, the offence of 'assisting' has been defined in s.4(1) Criminal Law Act 1967. This provides that:

Where a person has committed an arrestable offence, any other person who knowing or believing him to be guilty of the offence or some other arrestable offence, does without reasonable authority or reasonable excuse act with intent to impede his apprehension or prosecution shall be guilty of an offence.

As yet there is no case law directly relating to a psychologist withholding information about an offence that was described by a client, and it is likely that for an offence to be committed it would require a positive act on behalf of the psychologist intended to impede the apprehension or prosecution of the offender.[116] In common law, inaction by a psychologist may be regarded as 'complicity through omission to exercise control'. This recognises that in certain limited circumstances a person may be incriminated by their failure to act. Once again there is as yet an absence of relevant case law. It is likely that whether or not a psychologist was guilty of an offence would rest on whether they had a right to control the client. This may occur if the offender was detained under section of the MHA and the therapist was the responsible medical officer or nurse using the powers invested in them under the Act. Although this may not currently impact on psychologists, proposed MHA reforms and the potential introduction of the 'clinical supervisor' role could change this situation.

5.2 BPS Code of Conduct

In addition to the law of the land, chartered clinical psychologists are also bound by the British Psychological Society Code of Conduct[117] and should make sure that they are familiar with it.

The Division of Clinical Psychology of the BPS has published a supplement to the Society's Code of Conduct, in the form of *Professional Practice Guidelines*,[118] providing specific guidance to clinical psychologists. These guidelines describe the components of good standards of practice that will ensure the delivery of the highest quality services by clinical psychologists. Psychologists who work with people who show challenging behaviours should be familiar with the *Professional Practice Guidelines*.

The *Code of Conduct* (BPS, 1991) makes a general statement:
In all their work psychologists shall value integrity, impartiality and respect for persons and evidence and shall seek to establish the highest ethical standards in their work. Because of their concern for valid evidence, they shall ensure that research is carried out in keeping with the highest standards of scientific integrity. Taking account of their obligations under the law, they shall hold the interest and welfare of those in receipt of their services to be paramount at all times and ensure that the interests of participants in research are safeguarded.

As people with learning disabilities who show challenging behaviour are in receipt of psychologists' services, it is clear that their interest and welfare must be paramount.

The Code of Conduct then goes on to provide more detailed guidance on four areas:

- competence;
- obtaining consent;
- confidentiality;
- personal conduct.

Competence
Psychologists need to maintain and develop their professional competence, and recognise their limitations, ensuring that they work within the limits of their skills. The BPS has published a set of enabling guidelines[118] in order to facilitate the continued professional development of Chartered psychologists.

Consent
Psychologists can only carry out interventions with the valid consent of participants. This requires providing accurate and not exaggerated information to the service user, ensuring that the person is giving free and informed consent and that they know that they can withdraw their

consent at any time. Detailed discussion on these issues can be found in Sections 5.1 and 9.

The Code of Conduct recognises that it may be difficult for people with learning disabilities, those living in institutions or people detained under provision of the law to give valid consent and urges psychologists to recognise and uphold their rights. After consultation with colleagues, the psychologist needs to weigh up the balance between the duty of care (i.e. to provide an effective intervention for a challenging behaviour that puts the person or others at risk) and the obligations to intervene only with a person's valid consent. It is important that the service user is involved in the process as far as is possible.

Confidentiality

Psychologists must take all reasonable steps to preserve the confidentiality of information acquired through their professional practice or research, and protect the privacy of individuals or organisations about whom information is collected or held. Confidentiality is to be kept subject to the requirements of law.

The Code is clear that confidentiality may be breached in exceptional circumstances where there is sufficient evidence to raise serious concerns about the safety or interests of recipients of services, or about others who may be threatened by the recipients' behaviour. In such circumstances, prior consent to disclosure should be sought if possible. Failing that, the psychologist should consult with an experienced and disinterested colleague, unless the delay caused by seeking this advice would involve a significant risk to life or health. Within each NHS Trust there will be a 'Caldicott guardian' whose advice may be sought. The identity of individuals and organisations should not be revealed either deliberately or inadvertently without their express permission. The ability of people with learning disabilities to give valid consent to disclosure is again problematic. Similar considerations should be applied as with ability to consent to treatment.

It should be noted that the confidentiality of organisations is to be respected as well as that of individuals.
The majority of psychologists in learning disability services work in teams, where it is common practice to share information about both individuals and organisations.
People with learning disabilities (and perhaps especially those whose behaviour is challenging to services) are often known to teams for many years and it is too easy for them to acquire 'reputations' which are not respectful. Psychologists must beware the dangers of gossiping about people who use their services. They must also ensure, however, that they do pass on accurate information (e.g. about risky behaviour presented by the person, or of abuse perpetrated on them) when this is necessary to prevent harm.

Personal conduct

The BPS Code of Conduct also provides guidance about a psychologist's personal behaviour and conduct:
Psychologists shall conduct themselves in their professional activities in a way that does not damage the interest of the recipients of their services … and does not undermine public confidence in their ability to carry out their professional duties.[120]
Specifically, psychologists should not work when their practice is impaired through alcohol, drugs, illness or personal stress. They should not exploit their professional relationship with people to gratify their personal desires or to secure financial benefits. They will take steps to maintain adequate safety standards at work. They will not allow their professional responsibilities or standards of practice to be swayed by considerations of religion, race, age, nationality, party politics, social standing, sexual orientation, class or other extraneous factors. A client's learning disability would clearly be relevant here: a psychologist must not apply lower standards of practice because of a person's disability.

Psychologists also have the responsibility to act when they suspect misconduct by a professional colleague. If this cannot be addressed by discussion with the person concerned, then the psychologist must bring it to the attention of those with the responsibility to investigate it.
In addition to the BPS *Code of Conduct*[120] and the DCP *Professional Practice Guidelines*,[121] psychologists should also be aware of other relevant documents from the professional body. These include:

- DCP – *Guidelines for Clinical Psychology Services*.[122] This document sets out to clarify the standards that can be expected of psychology services. These concern the generic non-clinical aspects of services rather than specific clinical interventions and procedures.
- DCP – *Core Purpose and Philosophy*.[123] This includes sections on the philosophy, purpose and aims of the profession.
- DCP – *Guidelines for Continuing Professional*

Development.[124] This sets out guidelines that will facilitate the continuing professional development of all qualified clinical psychologists to ensure that they maintain their professional competence to provide the psychological services they are offering or agreeing to offer.

- DCP – *Clinical Psychology and Case Notes: Guidance on Good Practice*.[125] This provides specific guidance for clinical psychologists based upon the requirements outlined in *HSC 1999/53 – For the Record*.[126] It sets out to ensure that clinical records are properly controlled, readily accessible, available for use, and disposed of or archived properly.
- *DCP Information Leaflet No.6 – Guidance on clinical psychology workforce planning*.[127] This document provides guidance on the development of an appropriate clinical psychology workforce within local health services. Recommended staffing levels are provided for services for people with learning disabilities which would include people whose behaviour challenges services.
- BPS – *Working in Teams*.[128] This document sets out guidance for clinical psychologists in terms of responsibility and accountability issues in the delivery of multidisciplinary health and social care.
- DCP – *Policy and Guidelines on Supervision in the Practice of Clinical Psychology (2003)*. This document sets out guidance to assist psychologists in their understanding of supervision, the general context in which it takes place, what is involved in supervision, its relationship to CPD, who needs it and how often. It is the responsibility of clinical psychologists to ensure that they keep themselves professionally updated.

5.3 Local policies

The psychologist must ensure that he or she is familiar with local policies and procedures and has ready access to them for reference. The kinds of local policies that are likely to be relevant to interventions for challenging behaviour include:

- adult protection policies
- child protection procedures
- policies on the use of restraint
- policies on the ethical use of behavioural approaches
- policies on the ethical use of medication

It is recommended that local groups of psychologists adapt this section of the guidelines in line with their local situation.

5.4 Personal ethical beliefs

Psychologists need to be familiar with all the formal and legal requirements, but they must also be self aware, self-questioning and open to constructive criticism. A personal sense of 'something being wrong' is essential at times to alert us to possible bad practice or abuse. Neglect and various other forms of abuse are risks faced by many people with learning disabilities, and particularly those who are challenging.[129] [130] The clinicians' conference identified the importance of attending to 'uneasy feelings' about the work of other people or ourselves. Challenging behaviour may be a response to a damaging environment or relationship and this possibility should be considered when working with people who are challenging.

Psychologists must also be alert to the possibility that they may be mistaken or simply wrong in their assessments and interventions. People who are challenging may evoke difficult feelings in psychologists just as much as anyone else and such feelings may influence judgements. As articulate, paid employees with relatively high status in the settings in which we work, we must recognise that we are in a position of considerable power in comparison with people with learning disabilities and many of the people who work directly with them. People may acquiesce or be reluctant to challenge our views directly because of this inequality in power and status. We need to be proactive in seeking out both positive and negative feedback on the assessments and interventions we carry out.

Local psychology departments need to implement policies of clinical supervision and audit in order to ensure good ethical practice. Where clinical psychologists work alone, they should take particular care to ensure that their work is regularly and frequently reviewed by experienced colleagues.

We recognise from our clinical experience the difficulties of working within constrained resources, when the urgency of clinical need can sometimes drive us to working at the limits of our competence or beyond. Nevertheless, we believe it is particularly important under these circumstances to be clear about our minimum standards, so that we are able to provide a service which is both realistic and competent.

We would recommend that psychologists are clear about their limits with referrers and colleagues, and negotiate with them about what can or cannot be provided with the skills and resources available.

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6. Structure of the guidelines

The guidelines are presented in two parts:

1. *Core guidelines*
   The first part describes the *process* of working with individuals who present challenges. This section (Section 7) contains three core guidelines which can be used to provide a structure or framework for the psychologist's work.

2. *Detailed guidelines*
   The second part (Sections 8–14) describes the *content* of what might be done in greater detail. Guidelines are presented for each stage of the pre-assessment (Section 8), assessment (Section 10), formulation (Section 11), intervention (Section 12), evaluation (Section 13), and feedback process (Section 14).

6.1 Format of the guidelines

The actual guideline is presented first, followed by an indication of the level of evidence to support it and whether it should be seen as 'good' or 'essential' practice.

6.2 Level of evidence

For each guideline, there is an indication of the level of evidence that supports it, using the categories from the North of England project.[132]

Level 1: evidence from well-designed randomised controlled trials, meta-analyses or systematic reviews.

Level 2: evidence from well-designed cohort or case controlled studies (this includes well designed single case (n=1) experimental studies).

Level 3: evidence from uncontrolled studies or clinical consensus.

6.3 Good and essential practice

Bearing in mind the limitations of the literature which has been outlined in the section on the evidence base above, and because of the ethical concerns of clinical psychologists, we have chosen to make a distinction between *good practice* and *essential practice*, in addition to describing the level of evidence from the literature.

The majority of the guidelines describe *good practice* that should be followed by a competent psychologist. The language used is 'should' or 'ought'.

There are some guidelines, however, which we believe are *essential practice* and must always be followed. If they are not adhered to, there is a risk of bad practice. These guidelines use the term 'must' or the definition of a minimum acceptable standard. The essential practice guidelines can be seen as constituting a minimum standard of practice for psychologists.

Each guideline is therefore followed by the statement that it is either 'good practice' or 'essential practice.'

Where necessary, there is a definition or clarification of terms used in the guidelines. There is also a brief review of the evidence base and clinicians' views, together with a discussion of ethical concerns.

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7. Core guidelines – a framework for working with challenging behaviour

7.1 Core guideline A: An individualised process

In order to work effectively with someone whose behaviour is challenging services, a clinical psychologist must take into account that person's unique strengths and needs, and their unique social context.

Level of evidence to support this guideline: 3
Essential practice

In practice it is difficult to assess the level of evidence to support this guideline. There is negative evidence to indicate that failure to work in an individualised way leads to ineffective or even harmful practice. For example, failing to identify or misidentifying the function of a behaviour can lead to the reinforcing and hence increasing of a behaviour which is harmful to the person or others.[133 134] Two of the commonest functions of challenging behaviour are thought to be social contact and social avoidance. [135 136] These are opposites and to provide the same response to the behaviour (regardless of the person and the context) would result in completely different outcomes.[137]

There is a strong belief among clinicians that effective and ethical work must focus on individual needs and circumstances. Again this is perhaps based on the experience of difficulties caused by failure to work in an individualised way, as well as a commitment to seeing people with learning disabilities as unique individuals. Equally, clinicians believe that an assessment and intervention should not just focus on the challenging behaviour and its consequences. The person's opportunities for development, quality of life, choice, happiness and respect from other people must also be considered.

Person Centred Planning has been adopted as a cornerstone of the recently issued Department of Health policy for the health and social care of people with learning disabilities in the UK: 'A person-centred approach will be essential to deliver real change in the lives of people with learning disabilities' (p.5).[138] Other sections of the White Paper identify Person Centred Planning as a key means of implementation in respect of service co-ordination, improving outcomes, and achieving better partnerships between professionals and people with learning disabilities and their families.

Set in this policy context, it is perhaps surprising that whilst there have been anecdotal reports on the usefulness of Person Centred Planning, there have been few formal evaluations.[139 140 141 142 143 144 145 146]

Within the literature, there is an increasing use of the term 'Positive Behaviour Support' (PBS).[147] This approach has emerged from three major sources: applied behaviour analysis, the normalisation/ inclusion movement, and person-centred values. PBS integrates the following elements into a cohesive approach: comprehensive lifestyle change, a lifespan perspective, ecological validity, stakeholder participation, social validity, systems change and multi-component intervention, emphasis on prevention, flexibility in scientific practices, and multiple theoretical perspectives. The application of many of these characteristics will be evidenced in the development of the guidelines.

This guideline does not imply that the intervention will necessarily be an individual one. Assessment of the individual and his or her environment may indicate that the intervention needs to take place at a systemic or organisational level.

7.2 Core Guideline B: The basic process

When clinical psychologists work with people who show challenging behaviours, they should follow a coherent basic process, consisting of the stages shown in Figure 1.

This process should be seen as cyclical, with new information refining the formulation and making the intervention more focused and effective.

Given the persistence of severely challenging behaviours, work with people whose behaviour is severely challenging is likely to be long term.

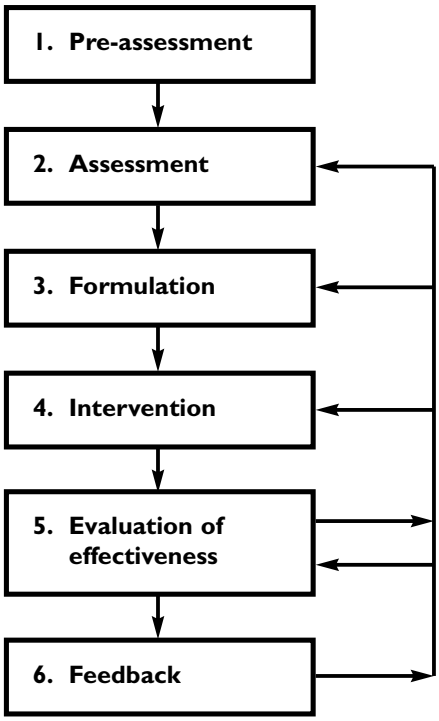


Figure 1.

Level of evidence to support this guideline: 3
Good practice
This guideline is presented as a useful schema to help structure assessment and intervention for challenging behaviour. It has not been evaluated other than through clinical practice and the consultation processes for these guidelines.

There is evidence to support the persistence of much severely challenging behaviour, but also evidence to show some variability over time and over settings.[148 149 150]

This model is of course a restatement of the familiar 'scientist practitioner' model,[151] where the psychologist defines the problem, investigates it, develops a hypothesis, tests the hypothesis, revises it etc. There has been a recent re-emphasis on this model in the literature on challenging behaviour, with new descriptive accounts of functional analysis.[152 153] Repp,[154] for example, describes three stages:

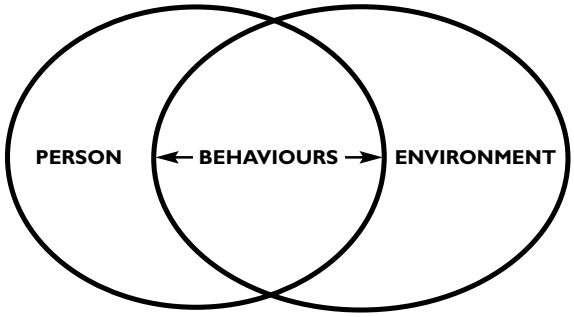
1. hypothesis development (e.g. by interview and rating scales);
2. hypothesis confirmation (e.g. by direct observation and descriptive analysis);
3. hypothesis testing (by analogue assessment or by intervention).

In this approach, the accuracy of an assessment and the effectiveness of an intervention is tested out systematically case by case. Practice is guided by the evidence as it is collected.

7.3 Core Guideline C: Essential elements

Any psychological assessment and intervention for challenging behaviour must include consideration of three elements:

1. the person;
2. his or her environment;
3. the behaviours which are challenging,
and the interaction between these elements.



Level of evidence to support this guideline: 3
Essential practice

'The person' is used to mean all aspects of that individual, including developmental, social and interpersonal history; abilities and disabilities; acute or long-term medical conditions, and physical and psychological characteristics.

'Environment' is used to mean the social and interpersonal milieu as well as the physical environment. It includes family and carer relationships, staff structures and organisations, timetables and programmes, buildings and facilities within them, neighbourhoods and the wider social context.

'Behaviours' need to be understood and defined precisely, given the very broad sweep of the term 'challenging behaviour.' At times the absence of an expected or necessary behaviour may constitute the challenge, as well as or instead of a behaviour which is overtly disturbing.

The nature and definition of challenging behaviour is that it is behaviour that occurs in a social context, in an environment. It is not acceptable clinical practice to ignore environmental factors in the creation and maintenance of challenging behaviour. Equally, individual characteristics, whether inherited or acquired, must be recognised and incorporated into the assessment, formulation and intervention.

For example, a common explanation of challenging behaviour is that 'they are doing it for attention'. There is evidence from analogue studies[155] that challenging behaviour may be maintained by social reinforcement. However, there are clear individual differences. For some individuals, perhaps because of autism or a history of abuse, inappropriate social reinforcement is highly aversive, whereas other individuals appear to crave a great deal of social reinforcement and become distressed and lonely when alone. There are also great differences in environments. It is essential to assess the amount of social contact or social deprivation in a person's environment. Few people had the chance to become satiated with social reinforcement in the learning disability institutions of the 1960s, and the level of social interaction in many community settings, particularly for more disabled people, remains frighteningly low.[156] [157] [158] If social attention is believed to be reinforcing someone's challenging behaviour, both individual and environmental characteristics need to be assessed – and the interaction between the two is likely to be very significant.

Where there is an underlying individual genetic cause for a particular behaviour, environmental factors can be used to reduce the frequency, severity and impact of the problem. An example of this would be work with people with Prader-Willi syndrome. Their biological make-up gives them an overwhelming desire to eat; this desire often leads to challenging behaviours related to food; but the challenging behaviours are still amenable to psychological and environmental interventions.[159]

Challenging behaviour may be secondary to physical or mental illness in the individual, which needs to be treated.

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8. Detailed guidelines – Pre-assessment

8.1 Pre-assessment

Definition: Pre-assessment is defined as that stage of preliminary information-gathering which helps shape the initial focus of a psychological assessment. Information may be given in a referral form or letter, but often needs to be supplemented by eliciting further details from the referrer or other key people.

The term 'pre-assessment' was used by Toogood and Timlin (1996)[160] in their review of functional assessment measures. They advocate the use of a pre-assessment stage to help create a systematic and efficient assessment.

As a new concept, it has not been evaluated in the literature and has no formal evidence base. Nevertheless, for psychologists working primarily in community settings it is a necessary and frequently time-consuming part of their work. We are recommending that this stage should be recognised as essential good practice.

Many services find it helpful to have a form to collect pre-assessment information at the referral stage.

8.2 Content of pre-assessment

The psychologist should make sure that he or she has essential, basic information available at the start of working with someone who challenges.

This information should include key facts about the person, their environment and the challenging behaviour. This is likely to include information to help with the 'risk screening' process.

Records of previous assessments and interventions should be acquired.

Level of evidence to support this guideline: 3
Good practice

As well as the person's name, address, telephone number, date of birth, it is helpful to have a brief description of how to communicate with the person (whether they use a signing or symbol system; first language; whether they can read appointment letters; whether they can talk to the psychologist about themselves.) Toogood and Timlin[161] suggest that an awareness of factors such as degree of disability, presence of sensory impairment and verbal ability will help the psychologist select the most appropriate combination of assessment methods.

It is also useful to know what kind of setting the person is living in – family home, group home, hostel, supported living etc.; whether there are any arrangements for respite care; whether the person attends a day centre, school or college; whether they carry out any paid or voluntary work or are on a training project. It is helpful to have an indication as to whether the challenging behaviour is occurring in all or just one or several settings. Variations between settings can be useful in generating ideas about possible environmental factors contributing to the behaviour.

Names of keyworkers and service managers, important family member and other professionals involved with the person should be elicited. All these people are potentially important informants about the person and the behaviour, and interventions which may have been tried earlier. There is some evidence that levels of training and education in staff make a significant difference to their ability to complete questionnaires, ABC charts etc.[162] Staff attitudes to the behaviour are also likely to impact on how they record or report it.[160] An awareness of the skills and experience of staff in different settings can help a psychologist select appropriate assessment methods.

A referral for 'challenging behaviour' needs further clarification – what are the behaviours and who is being challenged by them? Has there been one specific serious incident or is there a history or pattern of incidents? Is it a new behaviour or a well-established one? An idea of the severity of the problem can help determine level of risk and urgency. Frequency can also be used in considering what kind of recording methods are likely to be useful to elicit assessment information. High frequency behaviours can be assessed by direct observation, for example, whereas low frequency but high cost behaviours will

probably need to be assessed by reports from others.[163] It is likely that some of this information will be gathered as part of a process for risk assessment.

Previous work with the person who is challenging should always be reviewed; at the pre-assessment stage old notes and records should be obtained.

8.3 Purpose of pre-assessment

Pre-assessment should provide practical information about how to make contact with the person who challenges and other key people who live or work with him or her.

It should enable the psychologist to make a constructive and focused start to an assessment.

Level of evidence to support this guideline: 3
Good practice

The psychologist needs to know the best way to approach an individual who has been referred because they present challenges, in order to establish a good rapport with the person and the important people in his or her life. The psychologist also needs to know, very practically, where to meet them and when.

It is important for the psychologist to identify other staff who are working with the person concerned, so that a consistent and coherent multi-disciplinary approach can be implemented.

8.4 Risk assessment

The degree of risk to the person and others must always be assessed.

Level of evidence to support this guideline: 3
Essential practice

The psychologist must not lose sight of the fact that much challenging behaviour presents a serious risk to the person and others – to physical and mental health; to leading a full, valued and rewarding life. High level of risk is a compelling indicator of the need to ensure that a reactive behaviour management strategy[164] [165] is in place as soon as possible. The level of risk will influence the urgency of the response, but the psychologist must not make recommendations on the basis of a very incomplete assessment, and needs to make sure there is enough time to develop a good behaviour management strategy. During this time, the psychologist must be sure that the person is in an environment that is as safe as possible for everyone.

In many authorities the Care Programme Approach (CPA)[166] has been adopted as the mechanism for ensuring the co-ordination of the care provided to people with learning disabilities who display severely challenging behaviours. Risk assessment and risk management are central to the CPA process. CPA forms a key component of the Mental Health National Service Framework.[167] Although it is often a matter of debate amongst psychologists and psychiatrists as to whether 'challenging behaviour' should be included within a mental health framework, there are potential advantages of adopting the CPA framework for people with learning disabilities who present significant challenges. Each service should have a robust risk assessment and risk management process, whether or not it is as part of CPA. Psychologists must ensure that they follow local procedures.

The psychologist needs to work in collaboration with other professionals and service managers when there are situations where people are at risk, and take responsibility for ensuring that there is a mutual clarity about roles and expectations of what will be done by whom.

If a situation appears to be unsafe with an immediate risk of injury to the person or others, there are other possible courses of action, depending on the structure of local services:

- Additional members of staff can be brought in to either a family home or a residential setting to relieve stress on carers and provide a safer environment
- Emergency respite care may be available in a safer environment.
- Admission to a hospital unit on a voluntary basis or under section of the Mental Health Act 1983 if this is appropriate. In this case the psychologist needs to involve other professionals who have the statutory responsibility for admission under the Mental Health Act. All psychologists must ensure that they are familiar with the workings of the Mental Health Act 1983.

If the person has committed an offence such as assault, there must be clarity about the legal situation, and whether a prosecution can or should be brought.

Similarly, where the person has breached local agreements or policies, such as adult abuse policies, there needs to be clarity about what procedures are being followed.

As well as a direct physical or psychological risk to the person or others, there may be a risk of the loss of a valued part of a person's life, such as a job, college place or day or residential placement. There may be a risk of restrictive practices being applied, or the person's quality of life suffering through negative attitudes created in staff or families as a result of the challenging behaviour.

The psychologist should also be aware that there may be a risk to himself or herself and that there is a need to keep oneself safe and not take unnecessary risks. Local health and safety or violence at work policies should be available o cover these areas.

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9. Guideline on consent

9.1 Consent

Whatever form of assessment and intervention is proposed, the capacity of the person with challenging behaviour to give valid, informed consent must be assessed.

As far as possible, the person with learning disabilities must be asked to give their consent to assessment and intervention.

Family members and staff should also be provided with information and asked for their consent if they are the focus of an assessment or intervention.

Level of evidence to support this guideline: 3
Essential practice

This guideline is derived from an ethical imperative, rather than the evidence base, but must be clearly seen as good practice. Detailed discussion concerning the legal position with regard to 'capacity and consent' to treatment can be found in Section 5.1.

Information about psychological interventions must be presented in a clear and user-friendly manner.

The information should include:

- a full description of the procedures or techniques;
- an explanation of what is expected of the person with the learning disability, the psychologist and any others involved;
- any risks of the intervention;
- its likely effectiveness (from the literature and from the psychologist's clinical experience);
- alternative approaches and their costs and benefits;
- the consequences of not carrying out the intervention.

Where a person with learning disabilities is thought to be unable to give informed consent because of cognitive or communication difficulties, it may be helpful to seek the views of a fully informed advocate. It is accepted good practice that in such circumstances, professionals should consult with the person's family, other professionals, and an advocate, in a multi-disciplinary meeting. However, it should be noted that at present no one may give proxy consent for another adult, whatever the level of disability, although this situation is under review.[168] [169] [170]

The psychologist should also ensure that his or her work is supervised and reviewed by experienced colleagues. Particular care should be taken when the psychologist is using innovative techniques or approaches that have not previously been used with people with similar learning disabilities, or where established procedures raise ethical concerns or unease.

For consent to be valid,

- the person must be given the information (as described above),
- they must understand the information
- they must give their consent without any kind of coercion.

In order to enhance a person's ability to understand the information relating to a decision, consideration will need to be given to how the information is put across. This will need to be provided in accessible language, perhaps in small chunks, with pictures, and on repeated occasions.[171] It is important that the service user understands the information in broad terms, rather than needing to be able to understand all the details. The Department of Health has funded the Norah Fry Research Centre to produce evidence-based guidance on accessible information for people with learning disabilities. The project 'Information for All' is due to be completed in 2004. Their early review of the evidence identifies a number of potentially useful resources to help psychologists make the information more accessible to people with learning disabilities.[172] [173] [174] [175] [176] [177]

A similar level of informed consent should be sought from staff or families where they are the focus of a planned assessment or intervention. Written contracts are recommended as a way of ensuring that staff or families know what is happening and are clear about expectations of both them and the psychologist.

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10. Detailed guidelines – Assessment

10.1 Assessment

Definition: Assessment for challenging behaviour is the process of collecting and evaluating information about the person, the social, interpersonal and physical environment and the behaviour which is challenging. The information needs to be reliable and pertinent.

Assessment is a distinct and essential stage in the process of working with people who show challenging behaviour.

It is a necessary precursor to any psychological intervention. There may be an urgent need to 'do something' about the challenging behaviour. Psychologists may feel themselves to be under a variety of pressures to carry out an intervention. However, if such an intervention is not based on an assessment and formulation, it is unlikely to be effective and may even result in the challenging behaviour becoming worse.

When the challenging behaviour presents a severe risk to the person or others, it may sometimes be necessary to suggest a reactive behaviour management strategy on the basis of a brief assessment, including a review of previous interventions, and a preliminary formulation. If this is the case, it needs to be made clear that further assessment and reformulation will lead to a review of the original reactive strategy, and revision if necessary.

An argument has been put forward that assessment may not always be essential, and the delay to starting interventions may be unacceptable to parents.[178] However, in this study, interventions were not randomly assigned and there was in practice a shortened period of assessment.

The weight of the evidence available in the literature indicates that the most effective way of assessing challenging behaviour is to carry out a functional assessment.[179] [180] Functional analysis may be one format used for a functional assessment. The outcome of meta-analyses is that prior functional analysis correlates with a successful behavioural intervention.[181]

10.2 Purpose of the assessment

Assessment should serve three purposes:

1. **It should collect enough information to lead to a coherent psychological formulation.**
2. **It should lead to the selection of an intervention plan which fits the person and their environment.**
3. **It should establish a baseline so that the effectiveness of any intervention can be measured subsequently.**

Level of evidence to support this guideline: 3
Good practice

Assessment for formulation

Assessment is part of the process of working with people who show challenging behaviour. Enough information needs to be found and evaluated for the psychologist to be able to make sense of what is happening and come to a psychological formulation.

Being able to reach a reasonable hypothesis about the function of a behaviour is one sign that the assessment process has been adequate.

Assessment leading to an intervention plan which fits the person and their environment

The concept of 'goodness of fit' has been applied recently to interventions for challenging behaviour.[182] [183] An intervention needs to fit with the values and characteristics of the person with a learning disability, the people around him or her and their social, cultural or organisational environment.

Definition: 'Goodness of fit'

When contextual fit is high or good, a support plan and its components are consistent with, or highly compatible with, the values and skills of key stakeholders and plan implementers; readily sustainable given the resources and constraints

> of the environments, conditions and systems where the plan is implemented; and suitable to the unique needs of the person with problem behaviors. Put simply, the support plan works well for (i.e. makes a good fit for) the person and the environments where it is being implemented.[184]

It follows from this that a necessary part of the assessment process is getting to know the person and the values and skills, resources and constraints of the environments which support him or her. There is some evidence that failure to do this will limit the initial effectiveness and longer term maintenance of interventions.[185]

Baseline measure

The third purpose of assessment is to establish a baseline measure before any intervention so that the effectiveness of the intervention can be assessed.

Definition: A baseline is a measure of a person, a behaviour or an environment which is taken before an intervention starts.

The measure should be of something that is:

- clearly specified;
- observable or subject to reliable reporting by the person or others;
- replicable by other colleagues;
- relevant to the perceived need or target for intervention.

The baseline measures should match the targets for intervention. If for example, an intervention is aimed at changing staff attitudes, then those attitudes should be measured before the intervention. If an intervention is aimed at reducing challenging behaviours, then those behaviours should be measured before and after an intervention.

Self-report can be used to establish a baseline measure of psychological health or well-being, when the person is able to communicate information about his or her inner experiences.

If baseline measures are not taken, then the success or failure of an intervention can only be guessed at.

It can be helpful to take additional baseline measures of behaviours or attitudes that are not being targeted in a specific intervention, so that there is an internal control for measuring the effectiveness of the intervention, and any generalisation effects or 'symptom substitution' can be identified.

When the challenging behaviour is having an impact on other areas of the person's life, as is almost invariably the case, then it is important to assess that impact. This could involve taking baseline measures of aspects of the person's life, such as quality of life, levels of engagement in positive activities or use of restrictive practices by staff.

Successful outcomes for psychological interventions may be demonstrated if there is an improvement in quality of life, for example, or in a reduced use of physical restraint by staff, even if the frequency of the behaviour has not significantly changed.[186] Consideration should be given to obtaining the views of the individuals themselves regarding their perspectives on the impact of their behaviour.[187]

10.3 Extent of the assessment

Assessment should collect relevant information about the person, the environment or settings they live or work in, and the behaviours that are challenging to services and families.

Where a particular person or service setting is already well known to the psychologist, existing information should be reviewed and its current accuracy checked by interview and observation.

Level of evidence to support this guideline: 3
Good practice

An assessment for challenging behaviour needs to encompass all three elements of the person, the environmental setting and the behaviour. A partial assessment will be much less effective.[188]

There needs to be a multidisciplinary assessment of an individual who is challenging, which will identify any medical, psychological or other difficulties. Consideration needs to given to the potential roles of the different members of the team in the assessment of people who show self-injurious or aggressive behaviour.[189] The psychologist may have a role in acting as an advocate for the person with learning disabilities if they are unable to access appropriate specialist

health care. The psychologist may also have a role in advising on psychological aspects of healthcare in people with learning disabilities (e.g. by the use of desensitisation techniques for fears or phobias of medical procedures).

Previous assessments and interventions should always be reviewed.

Although it can be helpful to know a person or family or a service setting well, it is important to review this information and see if any changes have taken place. The psychologist should guard against hearsay – many people with severely challenging behaviour develop reputations within a service, which can be prejudicial to an accurate assessment. Similarly, day or residential settings can acquire an image of being a good or bad service, which needs to be checked against the current reality.

10.4 Selecting a focus

Given the complex lives of some people living in community settings, and the likelihood that people will demonstrate more than one behaviour which is challenging, a focus should be selected for the initial stages of the assessment and this focus made explicit to the referrer and other key people.

The pre-assessment stage should help determine the initial focus for the assessment.

Relevant factors to consider in choosing an initial focus would include:

1. **The degree of risk of physical harm to the person and others which a particular behaviour presents.**
2. **The risk of loss of access to services or other opportunities for development and participation.**
3. **The levels of distress being experienced by the person and others because of particular behaviours in particular settings.**
4. **The hopes, capacity and motivation for change in the person and the settings.**

Level of evidence to support this guideline: 3
Good practice

There is some evidence to suggest that work with challenging behaviour is more likely to be successful if it is focused. For example, research which has looked at the effectiveness of teams working with people who present challenging behaviours suggests that teams with a clearer model of working and clearer management structure and leadership were more successful.[190 191]

Research that has looked at the effectiveness of an applied behavioural approach in some detail, would also indicate that specific behaviours need to be worked with in a focused way. For example, the function of a particular behaviour at a particular time in a particular setting needs to be assessed – the same behaviour may serve different functions under different circumstances.[192]
Given the prevalence of challenging behaviour in people with learning disabilities it will be necessary to prioritise work in some way. This needs to be considered at the stage of taking up referrals and also when prioritising work with a particular individual.

One of the challenges faced by clinicians is to balance the need to work effectively – which needs very intensive work at some stages – with the demand for a quick and accessible response to a large number of people. Good practice would indicate being transparent about resources and priorities in such a situation and discussing the criteria for setting priorities. Attention needs to be paid to how widely accessible services are.

This guideline suggest that prioritisation should be based primarily on severity of clinical need – the risk to the client and others and the distress that they are experiencing – but that the capacity of the person with a learning disability and families or carers to change the behaviour should also be considered.

Similarly, when a specific target for intervention is being selected, the severity of risk (including the risk of losing a good service) together with the scope for change should be used to help decide where to start.

Although a focus on just one challenging behaviour is often the most appropriate and straightforward way of starting an assessment, there is a risk that other challenging behaviours may increase as one decreases during the intervention stage. There is also the possibility that other challenging behaviours will decrease if the intervention is

able to generalise. If there are concerns about a range of different behaviours, it is helpful to collect at least outline data on more than the one target behaviour.

10.5 Assessment of the person who is challenging

Assessment of individuals should include:

1. **Their strengths – abilities, opportunities, resources.**
2. **Their needs – impact of disabilities, service and resource gaps in their lives, needs for further development, mental and physical health needs.**
3. **Their likes, dislikes and preferences and how they express these.**
4. **Their history – developmental, social, medical, history of use of services.**

Level of evidence to support this guideline: 3
Essential practice

Assessment of strengths

Assessing a person's strengths is important for identifying possible strategies for change. For example, if a person can express their thoughts and feelings verbally or in written or pictorial form, then this strength may be utilised in a psychological intervention. Strengths need to be identified so that they can be built on to promote positive behavioural change.

Identifying strengths can also help increase motivation to work together to make changes. Staff groups with strong positive values about people with learning disabilities can find it difficult and painful to look at problematic behaviour or the person's disabilities, and may need the opportunity to talk about the person's positive aspects and have these valued before looking at areas of difficulty. Conversely, where staff groups have developed a negative view of a person, helping them look at the positive side is an essential first step towards developing a positive intervention.

The need to assess strengths is based on clinical consensus and values held by psychologists, as it has not been evaluated in the literature.

Assessment of needs

Identifying an individual's needs for support because of underlying difficulties or disabilities should never be omitted from the assessment of challenging behaviour. In general terms, certain disabilities have been shown to be associated with challenging behaviour. There is a correlation between severity of learning disability and prevalence of challenging behaviour.[193] For example, in one study it was found that 33 per cent of people with profound learning disabilities also showed challenging behaviour. Impairment of communication, hearing, vision and mobility have also been shown to be associated with an increased risk of challenging behaviour.[194]

An increase in the prevalence of some particular forms of challenging behaviour has also been reported to occur in association with specific syndromes associated with learning disabilities. These include:

- occurrence of self-injurious behaviour, specifically hand and lip biting, among all people who have Lesch-Nyhan syndrome;[195 196 197]
- very high prevalence of self-injurious hand-wringing in Rett syndrome;[196]
- greater than expected prevalence of various forms of self-injurious behaviour in the Cornelia de Lange, Riley-Day and Fragile-X syndromes;[196]
- greater than expected prevalence of hyperkinesis, attention deficits and stereotypy in Fragile-X syndrome;[198 199 200 201 202]
- greater than expected prevalence of self-injury among people with autistic spectrum disorders;[203 204]
- high prevalence of challenging behaviours in Prader-Willi syndrome.[205 206 07 208 209 210]

The recent explosion of interest in the 'new genetics' is likely to lead to a substantial growth in knowledge about the behavioural manifestations or 'phenotypes' of a range of syndromes.[211 212 213]

Psychiatric diagnosis may be associated with challenging behaviour for some people with learning disabilities.[214] This is a complex area where definitions of terms are crucial (e.g. 'conduct disorder' in childhood may be used as a synonym for challenging behaviour). Different types of mental health problems produce very different types of challenging behaviour, ranging from the apathy and withdrawal of depression to wild excitement and over activity in hypermania. If someone is dually diagnosed, it is essential for the psychologist to have a clear understanding of the emotional, cognitive and behavioural components of his or her specific mental health problems. A similar level of awareness is required when a person is diagnosed as autistic as well as learning disabled.

There are three possible ways in which mental health problems may be associated with challenging behaviour:[215]

Challenging behaviour may be the atypical presentation of a mental health problem. It is possible that psychiatric disorders may be manifested in unusual ways among people with highly restricted language and adaptive behaviours. For example, circumstantial evidence suggest that some forms of self-injurious behaviour may constitute the atypical presentation of obsessive-compulsive disorder among people with severe learning disabilities.[216]

Challenging behaviour may be a secondary feature of a mental health problem. A range of challenging behaviours (including aggression and self-injurious behaviour) may occur as secondary features of affective disorders among people with severe learning disabilities.[220] [221] For example, a variety of clinical features may be indicative of depression among people whose level of disability makes it difficult for them to verbalise their feelings.[222] These features include somatic symptoms (e.g. headache and stomach ache), agitation, disturbances of sleep, appetite and bowel movements and loss of self-care skills.[223] [224] [225] [226]

Mental health problems may establish a motivational basis for the expression of challenging behaviours which are then maintained by behavioural processes. Some mental health problems may create an enhanced sensitivity to stimuli, or interpersonal difficulties or other factors which may create a climate in which challenging behaviour starts. Once started, other factors come into play to maintain the challenging behaviour. Depression, for example, may be associated with an unwillingness to participate in educational or social activities, thus establishing such activities as negative reinforcers (i.e., events whose termination is reinforcing). If the person has previously learned that challenging behaviours can terminate such aversive events, we would expect an episode of depression to be associated with an increase in challenging behaviour. In such a case it would be necessary both to treat the person's depression and to change the 'functionality' of the person's challenging behaviour.

It is also good practice to have a clear picture of any specific neuropsychological difficulties the person may have as a result of brain injury or impairment. Problems of attention, memory, problem-solving, etc. can contribute to the likely development of challenging behaviours. Epilepsy is very common in people with learning disabilities[228] [229] and its effects on the individual need to be understood and evaluated as part of the assessment process. Indeed, some evidence suggests an increased prevalence of challenging behaviour among people with epilepsy, both in general[230] and in relation to specific forms of epilepsy,[231] [232] Sleep problems may be associated with significantly increased challenging behaviours during the day.[233]

There is no evidence in the literature to confirm or disconfirm this part of the guideline. It is based on clinical consensus and the clinical experience of the problems caused by the failure to recognise the impact of someone's mental state or disability on their behaviour.

Assessment of individual likes and dislikes

It is important to assess a person's likes and dislikes for several reasons. A psychologist needs to be able to recognise how people, especially those with the most severe cognitive and communication disabilities, express their preferences.

One reason for this is in order to identify potential reinforcers which can be used to motivate changes in a person's behaviour and teach new skills. Another reason is so that aversive stimuli can be avoided.

'Aberrant motivation' should be considered in work with people with learning disabilities i.e. that individuals may be unusually sensitive to some reinforcers or desire large amounts of reinforcement.[234] This may be because of the person's inherent characteristics (as with the desire for food in Prader-Willi syndrome or sensitivity to noise in people with autism) or may be because of personal history and experience.

Being able to assess reliably how a person reacts to an intervention is an important component of assessing consent.

Families and staff who know a person with severe disabilities well, are often able to explain how they judge likes and dislikes. Facial expression and physical movements such as reaching towards or turning away, can be reliably used to assess preference in even the most disabled people.[235] [236]

The psychologist also needs to be aware of potential difficulties when assessing the likes and dislikes of more able people with learning disabilities, who may be overly

acquiescent, particularly with people in positions of power in their lives such as psychologists and other members of staff.[237 238]

Assessing the person's history
Taking a history puts the behaviours into a context and helps establish a 'good fit' between any proposed interventions and the person's life experiences. It may even help to avoid making the same mistakes twice.

History can be assessed by reviewing old case notes and by talking to the individual and to family members or staff who have known the person for a long time. The history should include:

1. a medical history which includes an account of the diagnosis or identification of learning disabilities and other medical or psychiatric conditions;
2. genograms (family trees) and accounts of family history;
3. history of contact with services and institutional care;
4. educational and employment history, including attendance at day centres;
5. social history – friendships and other relationships;
6. a historical account of challenging behaviours, where this is appropriate, including any offences;
7. an account of previous interventions and their effectiveness.

Taking a history is an important part of the assessment process, but a psychologist needs to be sensitive to the experience of parents or people with learning disabilities who may be asked to repeat their 'stories' to many different professionals.

There are no studies where the effectiveness of history taking has been evaluated, so this part of this guideline is based on clinical practice.

10.6 Meeting the person who is challenging

When at all possible, the person who is challenging should be interviewed as part of the assessment process.

As a minimum standard, the person must always be met face to face, and enough time spent with them for the psychologist to have a sense of them as an individual.

Level of evidence to support this guideline: 3
Good practice

This guideline is both a practical suggestion about how to assess a person effectively and reliably and a statement of an ethical principle.

The views of people with challenging behaviour about themselves, the people who live and work with them, their environment and the services they receive, and the reasons for their challenging behaviour should all be actively sought.

Where the person uses a signing or symbol system or a language which the psychologist does not understand, a competent interpreter should be sought. Where severe expressive or receptive communication difficulties make interviewing extremely difficult, additional time should be spent observing the person in different settings.

Studies have shown that depending on other people's reports of individuals alone, particularly when those individuals are challenging, is not a reliable method for collecting information.[239] Staff attitudes to the person and to their challenging behaviour tend to colour their reporting. This is particularly the case with retrospective reporting, with non-specific information (interpretation of events rather than detailed accounts) and with distance in time from events or characteristics being recalled.

There are well known difficulties with interviewing people with learning disabilities, including acquiescence,[240 241] suggestibility to leading questions[242] and feeling obliged to please an interviewer who is perceived to have high status.[243]

There is, however, a growing body of literature which addresses these difficulties and provides useful guidance. Interviews need to avoid closed yes/no questions and leading questions.[244] Pictures and symbols can be used to supplement the verbal content of questions and answers, although it should not be assumed that these are necessarily easier to understand for everyone. For reviews of these issues, consult the following references.[245 246 247 248]

Where the person with learning disabilities does not have the communication or cognitive skills to participate in

these kinds of measures, it is still important to get to know him or her. Observation of facial expression and other forms of non-verbal communication can provide reliable information about how a person thinks and feels, what they like and don't like and so on.[249] Packages such as 'Getting to know you' have been used to help structure this kind of assessment.

10.7 Assessing the environment – what to assess

Assessment of the environment should include:

1. **The physical environment**
2. **The interpersonal setting – relationships and values**
3. **The organisational setting – systems and processes in place to support the person.**

Level of evidence to support this guideline: 3
Essential practice

This guideline is based primarily on clinical consensus and the belief that challenging behaviour, by its nature, derives from an interaction between a person and the physical and interpersonal setting they are in. It follows that the environment needs to be assessed just as carefully as the individual. However, there are a number of studies which either describe the inter-relationships between challenging behaviour and aspects of the person's environment, or suggest mechanisms through which environmental variables may impact on challenging behaviour.
Any assessment of the environment that a person lives or works in needs to include psychological and organisational factors as well as the physical environment.

The *physical environment* may have an important influence on a person's behaviour. Elements to assess would include:

- size;
- comfort – heat, light, noise;
- location – access to community facilities, open spaces;
- safety.

Published evidence to support the need to assess the physical environment has highlighted the potential salience of noise and temperature,[250] crowding,[251] location,[252] music,[253] the presence of such idiosyncratic variables as small balls, puzzles and magazines,[254] and general environmental conditions.[255]

In assessing the *interpersonal and organisational setting*, a psychologist needs to take into account the network of people and relationships around the person whose behaviour is challenging. This might include:

- relationships with staff or family members and other service users;
- their beliefs about the person and the challenging behaviour;
- effects of the behaviour on them;
- interaction and engagement with the person;
- routines and practices;
- values and attitudes about disability and challenging behaviour, including cultural values;
- skills and resources available;
- organisational culture;
- family culture.

The evidence for the importance of assessing the interpersonal environment and its relevance to challenging behaviour comes from a wide range of studies. Behavioural studies have commonly identified social contact or social avoidance as common functions of challenging behaviour.[256 257 258 259 260]

In addition, evidence points to the possible role of a range of interpersonal and organisational variables, either as immediate precursors to episodes of challenging behaviour or as influencing people's capacity to work constructively with people with challenging behaviour.[261 262 263 264 265 266 267]

These include:

- *preceding interactions* such as preceding compliance,[268 269 270] task repetition,[271] critical comments from others,[272] the cancelling or delay of previous activities,[273] immediately preceding interactions,[274 275 276] temporally distant social interactions,[277 278] physical exercise,[279] the route taken to a setting[280] and time of awakening.[281]
- the *current context* for behaviour including such factors as preference and choice regarding concurrent activities,[282 283 284 285 286 287 288 289 290 291 292] the amount of non-contingent reinforcement available in the setting[293 294 295 296 297] and concurrent social interactions and the nature of surrounding activities.[298]

Studies of small houses supporting people with severely challenging behaviour in the community have indicated the importance of good management which provided support and motivation for staff as well as a positive environment for people with learning disabilities.[299 300]

Assessment of the person's environment before and after an intervention for challenging behaviour can look at the intervention's effectiveness in improving the person's quality of life as well as reducing challenging behaviour. Several authors have argued that these wider issues should also be assessed as 'meaningful outcomes'.[301 302 303 304]

10.8 How to assess the environment

Information about the environment should be sought from interviews with key informants. Views should be sought from more than one perspective in a service setting (e.g. managers and direct care staff.)

Relevant documentation should be accessed (care plans; person centred plans; individual program plans; activity timetables; statements of values; policies and procedures etc.)
Information from interviews and documentation should be supplemented by observation of the relevant environment or settings in action, preferably while the person is there.

Where the individual lives with his or her family for all or part of the time, the family member who is mostly responsible for the care of the person should be interviewed, and attempts made to meet and interview other family members who are significant in terms of the amount of time and influence that they have with the person.

Level of evidence to support this guideline: 3
Good practice

This guideline is derived from clinical consensus of good practice.
Environmental factors can be assessed by:

- direct observation;
- structured record keeping;
- interviews with key informants;
- questionnaires;
- reviews of relevant documentation.

There is no substitute for the structured and careful observation of the person with learning disabilities in the setting where the challenging behaviour occurs.

This can be done by the psychologist or by others (e.g. families, care staff) who have the skills and the opportunity (space and time) to do it.
Direct observation should look at both long-term, consistent features of the environment (such as the physical building) and those factors which fluctuate from day to day or even minute to minute (e.g. engagement or social interaction)

Concurrent recording of challenging behaviours by staff (using ABC charts) has been shown to be particularly unreliable where staff do not see the target behaviour as challenging.[305] It seems likely that the identification and recording of relevant environmental factors may also be affected by staff beliefs. Staff skill and level of training both generally and in the specific task of recording behaviours seem to impact on the reliability of recording.[306]

Using intensive techniques such as time sampling (when details of the person's behaviour and of the social and physical environment can be recorded to a pre-set format at a fixed time interval) or event sampling (when each time a certain event happens a series of data on concurrent activities or setting details can be collected) should help to reduce response bias in comparison with a more free-floating recording of an observation session.[307 308] However, these types of technique are onerous even with the use of a hand-held computer and care needs to be taken to avoid observer fatigue and loss of concentration. Video recording can identify activities and patterns of interaction but may miss some features of the physical environment such as room temperature.

Interviews with key informants – the people who spend most time with the person whose behaviour is challenging – are another valuable way of assessing environmental factors.[309 310] Several authors have produced structured or semi-structured interview schedules for the purpose of assessing challenging behaviours which include questions about environmental factors.[311 312 313 314 315]

The results from retrospective reporting accessed through interview may be no less accurate than concurrent recording[316] but is also likely to reflect the informants' beliefs about the challenging behaviour and attitudes to the person with a learning disability. This may have the disadvantage of biasing the accuracy of the recording, but potentially enables the beliefs and attitudes to be assessed at some level and taken into account in the full assessment process.

There are some standardised or systematic tools available for the assessment of aspects of the environment :

- broad aspects of quality of life;[317 318 319 320]
- quality of care;[321]
- family climate;[322 323]
- how much an organisation might meet targets informed by particular values;[324]
- social climate;[325]
- community attitudes to people with learning disabilities;[326 327]
- staff knowledge, skills and beliefs;[328 329]
- choice and autonomy for people with learning disabilities;[330]
- activity levels. [331]

It can also be helpful to review the documentation held about people and their environments – care plans, policy statements, guidelines etc. The presence of competent and comprehensive written information is obviously desirable, and its absence may be indicative of a range of managerial or resource difficulties. However, an assessment of the written material must always be supplemented by an assessment of actual practice, which is best carried out by personal interview and observation.

Assessment of quality of life and the person's well-being in a particular setting can serve three purposes:

1. It may help identify factors in the environment which are contributing to the challenging behaviour.
2. It may identify restrictions and losses of choice or opportunity, which are occurring as a consequence of the challenging behaviours.
3. It can suggest other or alternative meaningful targets for change (as well as the challenging behaviours) and provide a baseline measure of such targets.

10.9 Assessing the challenging behaviours – what to assess

Specification

The challenging behaviour(s) to be assessed must be specified clearly.

The behaviour must be described in terms which are:

- **clear and unambiguous**
- **measurable (by observation or self report)**
- **capable of future replication**

Onset

The onset of the challenging behaviour should be ascertained where this is possible.

Significant life events and changes of or within the environment should be noted.

The ways in which family or care staff responded to the challenging behaviour when it first started should be identified – if possible with the support of contemporary documentation.

Frequency, severity, duration

As a minimum standard, the frequency of the challenging behaviours must always be measured. The severity and duration of the behaviour(s) should be measured too, especially when there are definite fluctuations in either factor. Fluctuations over time and over setting should be identified and then recorded.

Level of evidence to support this guideline: 2

Essential practice

There is good evidence in the literature and from clinical practice to support the need to carry out a thorough and detailed assessment of the challenging behaviour as described in this guideline.

The behaviours to be assessed need to be described in unambiguous, observable, measurable terms. Another person needs to be able to replicate the measurement – and may well have to if anyone other than the psychologist is going to be collecting data in the various settings where the person with challenging behaviour lives and works.

Identifying the start of a behaviour can help suggest possible functions for it or may indicate how the person learnt a particular way of being challenging. Looking at fluctuations over time and setting can also be helpful in generating ideas of the function of a behaviour.

A baseline measure of the challenging behaviour must be established. If it is not, the impact of any intervention cannot be measured. This is relevant whether the intervention targets the behaviour directly or attempts to alleviate the

pain, boredom or distress, which may underlie it.
The most basic measure of incidence of challenging behaviour is a simple frequency count. See Guideline 10.11 below for methods of taking a baseline measure of behaviour.

10.10 Assessing the challenging behaviours – where to assess

Challenging behaviour should be assessed in the everyday settings of the person's home, school, workplace or community – wherever the behaviour may occur – unless this presents too great a risk to the person with challenging behaviours or others.

Level of evidence to support this guideline: 3
Good practice
It is very important to assess challenging behaviour in its social context. If this cannot be done because it is too risky, then important data may be lost. The psychologist will need to go to additional lengths (e.g., contacting additional informants) to compensate for this.

10.11 Taking a baseline measure of challenging behaviours

A baseline measure of the frequency, severity, duration etc. of challenging behaviours can be taken by

- **direct observation which is simultaneously recorded;**
- **direct observation which is recorded subsequently;**
- **self-reported accounts of past behaviour;**
- **accounts of past behaviour which are reported by others (e.g. carers).**

Attempts should be made to be as accurate as possible, using observation rather than post-hoc accounts and recording behaviours as closely as possible to the time when they occur.

The information may be collected either by the psychologist or by others such as care staff or family members in day-to-day contact with the person who is challenging. If other people are being asked to observe or complete recording sheets, the psychologist must make sure they have clear instructions and that they understand the rationale for recording the information and are well motivated and able to do so.
When psychologists ask other people to collect information about incidents of challenging behaviour, they must make sure that they retrieve the information collected regularly, reliably and frequently. It is not acceptable practice to set a task such as data collection and not follow it up.

People with learning disabilities who have the motivation and skills to monitor their own behaviour should be supported in doing this.

Level of evidence to support this guideline: 2
Essential practice
This guideline is based on a number of studies which looked at a range of questions about the most accurate and effective ways of collecting information about the incidence and functions of challenging behaviour.[332 333 334 335]

Once a decision has been made about which behaviours are to be assessed (see Guideline 10.9 above) the psychologist needs to decide on the best method of collecting accurate data for a baseline measure.

The relevant factors to consider are:

- the expected frequency of the behaviour:
  - high frequency behaviours can best be recorded by simultaneous observation and recording – the closer the recording is to an event, the more likely it is to be accurate;
  - very low frequency behaviours will probably need to be assessed by reports from the person with learning disabilities, if possible, carers who know the person well, people present at the time of the incident etc.;
  - information about low frequency challenging behaviours should be collected as near as possible to the time at which the behaviour occurred, while memories are still relatively clear.

- the impact or saliency of the challenging behaviour on the people being asked to record or describe it:
  - people will remember a highly salient incident of challenging behaviour more, but their memories of it are more likely to be coloured by their emotional reaction to it;
  - staff attitudes and beliefs about the person and the behaviour have been shown to effect the accuracy

of their reports.[336]

- the education, training and experience of staff members who are potential informants:
  - there is some indication that levels of training and general education in staff make a significant difference to their abilities to keep accurate records, complete charts, questionnaires etc.[337]
- the technology available to support observation and recording:
  - highly accurate frequency measures can be taken using hand-held computers;[338 339]
  - videos can be used effectively to record behavioural data for subsequent analysis by trained observers.[340]
- the possibility of collecting information from more than one informant:
  - if data can be collected independently from more than one source, then accuracy can be checked by inter-rater reliability checks.

It will be most appropriate to ask staff or family members to keep records of behaviour when people are skilled and motivated to carry out the recording, and when the behaviour occurs less frequently and less predictably (so that it is difficult for the psychologist to observe it). Where staff or family members are not experienced in this kind of work, the psychologist needs to provide clear instructions and sufficient training for them to be able to complete the task satisfactorily.[341] The psychologist can help motivate people by explaining the rationale for recording, but especially by ensuring that he or she comes back to collect the records promptly and gives feedback to people on the work they have completed. (These points were identified at the conference on good practice.)

People with learning disabilities can reliably keep records of their own behaviour if, like family members or care staff, they have the skills and the motivation to do so.[342 343 344]

The person with learning disabilities should be involved in the selection of a target behaviour to be monitored – the behaviour must be observable, measurable and meaningful to the person. The psychologist needs to be sensitive about asking a person to record behaviour of which they are ashamed or about which they feel angry or guilty.

A range of creative recording systems for people with learning disabilities have been suggested in the literature:

- tallies using pegs (like a cribbage board) or beads (as in an abacus) or marks on paper;[345]
- using pictorial representations of the target behaviours;[346]
- using verbal prompts, or automated tones, timers or other signals to cue recording using a time-sampling methodology.[347 348]

Some authors have suggested directly reinforcing the behavioural recording. However, for some people the feedback from reviewing the recording sheets may have a self-motivating aspect – challenging behaviours may reduce as they are being monitored and recorded.[349]

Formal measures developed for use with the mainstream population[350] can be of use but have to be adapted either verbally or in presentation format for all but the most borderline learning disabled client, thereby losing the benefits of standardisation. They are still useful however when given to the same person before and after an intervention (i.e. as an individualised measure).[351] Standardised psychometric tools have been used to measure the outcomes of cognitive behavioural and psychodynamic therapy with people with learning disabilities. People have been asked to complete the questionnaires before and after therapy. They are particularly appropriate in these therapies because the locus of intervention is the person's thoughts and feelings, which are perhaps most effectively measured by self appraisal. Examples of the use of questionnaires and inventories for pre- and post-intervention measures with people with learning disabilities include psychodynamic psychotherapy[352] and cognitive behavioural approaches.[353]

The process of collecting data for recording the frequency etc. of a challenging behaviour can also be usefully applied to collecting additional data to generate hypotheses about the function of the behaviour. (See guideline 10.12 below.)

10.12 Assessing the function of challenging behaviours

It is essential that a psychological assessment attempts to establish the function of challenging behaviours, in order to determine the correct basis for an intervention.

The most appropriate way of doing this will usually be through a functional analysis.

Level of evidence to support this guideline: I
Essential practice

Definition Functional analysis is a term which is used with different degrees of precision by different authors. The two main usages in psychological approaches to challenging behaviour are:

1. The attempt by a range of methods, including interview and recorded observation, to identify the function (used in its everyday sense of purpose or utility) of a particular behaviour in a particular context.
2. The specific behaviour analytic procedure where structured observation and other methods of assessment (interview of people in frequent contact with the person, use of standardised questionnaires) are employed to generate hypotheses about the challenging behaviour, antecedents which might be acting as stimuli for the behaviour and consequences which may be reinforcing it. These hypotheses are then tested out by experimental trial in either a real life or a more controllable analogue setting. The hypotheses that can be supported by experimental evidence are then used to derive interventions to reduce or eliminate the challenging behaviour.

The evidence base supports the use of functional analysis (in its second, stricter meaning) for interventions where the primary focus is the reduction or elimination of severely challenging behaviours in people with moderate, severe or profound learning disabilities. A correlation has been found between carrying out a functional analysis and successful outcome, measured by reduced challenging behaviour.[354 355 356 357]

This should therefore be the approach of choice where challenging behaviour is severe and the most urgent target for intervention.

There is general agreement that a functional analysis should follow three stages.[358 359 360]

Stage 1 *Hypothesis development*
Interviews or rating scales are used to generate hypotheses or rule out areas for further investigation;

Stage 2 *Hypothesis testing*
Direct observation and more detailed interviews are used to assess the accuracy of the hypotheses and identify contextual factors;

Stage 3 *Hypothesis refining*
Either experimental analysis is used to refine the working hypothesis or there is a direct move to intervention strategies which are used to check the accuracy of the hypothesis about the function of the behaviour.

Stage 1 – Hypothesis development
A good place to start is with interviewing the person with learning disabilities, care staff and family members about the challenging behaviour. People will have their own explanations of the behaviour which it is helpful to identify at an early stage – if they seem accurate then a lot of work is saved, but if not, going through the ideas together and working out ways of checking their accuracy is a useful process which can help people develop skills in working with people with challenging behaviour.

Interviews can follow a structured format[361 362 363 364] and may incorporate rating scales.[365]

However, the scales need to be used with caution because of difficulties with reliability.[366 367] A number of studies have been conducted to measure the reliability of scales such as the Motivation Assessment Scale,[368 369] the Verbal Behaviour Assessment Scale,[370] the Questions about Behavioural Function Scale.[371] A structured interview format can be helpful to generate a range of hypotheses about the function of the challenging behaviour and prevent premature closure.

Stage 2 – Hypothesis testing
Once hypotheses have been generated, these can be tested by monitoring behaviour in the person's everyday environment. A common way of doing this is by ABC chart.[372]
ABC charts, when used reliably and accurately, can be used to identify:

- **A**ntecedents to the behaviour:
  - setting conditions, particularly recent and immediate

ones;
  - specific triggers for the behaviour.

- **B**ehaviour – a record of the target behaviour and of variations (in severity, frequency etc.) in different settings and contexts.

- **C**onsequences of the behaviour
  - possible reinforcers (both positive and negative).

If people such as family members or care staff are being asked to keep ABC charts, the same considerations about motivation and skills apply as in the Guideline 10.8 above.

There are difficulties however with the reliability of ABC charts.[374] [375] [376]

They should be used with caution and mainly to measure basic information such as the rate of occurrence of challenging behaviour or broad variables in the environment such as time of day or location.[377]

The usefulness of ABC charts can be enhanced by:
- providing training in how to complete them;[378]
- having more than one person complete them independently and checking inter-rater reliability;[379]
- being very specific about what is to be recorded.[380]

Direct observation can be used with greater confidence, particularly with high frequency behaviours, to check out different hypotheses about the function of the behaviour. [381] [382]

It is advisable to structure direct observation using either time sampling or event sampling techniques. Because of the amount of data to be collected and analysed, it is also advisable to use a hand-held computer to collect the data[383] [384] [385] and either a standard spreadsheet package or purpose-designed software to analyse it.

Presentation of the data is another factor to consider. Simple bar charts and pie charts can be generated by standard computer spreadsheets and the visual representations of variation in behaviour can be vivid and easy to understand. Scatter plots[386] [387] are another graphic way of presenting data.

Multiple methods of data collection are generally recommended for the purpose of hypothesis confirmation.[388] [389] [390] [391] [392] This is because any one strategy has its flaws and biases. Attempts to check the validity of one approach against another have generally shown unsatisfactorily low levels of agreement,[393] [394] with different methods of assessment tending to identify different functions.

Stage 3 – Hypothesis refining

The hypotheses which have been generated can be tested out either by further direct observation of naturally occurring variables in the person's normal environments[390] or by manipulating factors in a controlled analogue setting to test out the hypotheses.[394]

In analogue assessment, the supposed antecedent (setting event or trigger) or reinforcer is either withheld or presented in a controlled way (perhaps interspersed with other conditions in an ABA type design), and contingent changes in the target behaviour are measured. The hypothesis about the behaviour is thus tested out in a classic experimental fashion. For example, rates of self injury might be assessed in different conditions such as with and without social interaction of different types such as disapproval, praise or demand.[395]

Although elegant, this can be difficult in practice:
- it requires a high level of control over the environment;
- it may miss contingencies which are operating in the person's 'real' environment;
- it requires skilled staff;
- it may take a very long time to identify the relevant functions;
- the results may not generalise outside the analogue setting (there may be unique contingencies operating there);
- the setting may be stressful and the process may be aversive for the person with challenging behaviour.

Testing out the hypotheses in the person's usual environment also requires a high level of skill and considerable time. Real environments are usually much less easy to control and unexpected variables can intrude. But there is a considerable advantage in working with the real settings where the challenging behaviour occurs.

Both forms of hypothesis testing are valuable and should

be used where there is behaviour which presents a major challenge in terms of its consequences for the person and others and when it has not proved amenable to less intensive forms of assessment.
Another way of testing out a hypothesis is by measuring the effects of an intervention. This is probably the approach most commonly used by British psychologists in day to day practice. Once a hypothesis has been confirmed through observation, an intervention is tried. The success of the intervention is seen as supporting the hypothesis. This has the advantage of being relatively quick. However, if the intervention has been based on the wrong premise and the challenging behaviour does not improve, the psychologist risks losing the confidence of the person with a learning disability, families and care staff and reducing their motivation to persevere with other interventions. This risk may be reduced if the psychologist makes it clear in advance that the intervention is based on a hypothesis and not a confirmed theory.

A recent development in functional analysis has been the greater refinement or 'fine tuning' of possible functions of challenging behaviour from broad categories such as 'social contact' to much more specific factors such as the verbal content of social interaction with particular individuals.[396]

The functional analytic approach was used traditionally for strictly observable behaviours, but has more recently been expanded to include cognitions or emotions or historical setting events (the person's history and experiences).[397] [398] There is a growing clinical belief that especially in people with milder or borderline learning disabilities, a behaviour analytic approach needs to be supplemented by work with cognitive and emotional factors.

Clinical consensus indicates that functional analysis in the first sense – the attempt to understand the purpose or meaning of a particular challenging behaviour – is always necessary, whatever the therapeutic stance of the clinician.
With systemic or organisational interventions, where the challenging behaviour is more likely to be conceptualised as an indicator of difficulties in a system which prevent the person's needs and choices from being attended to in a more helpful way, understanding the functional aspect of the challenging behaviour is illuminating. What the behaviour demonstrates about a system is likely to indicate focal points for interventions.

The process of psychotherapy is also a struggle for establishing meaning, and needs to address areas such as challenging behaviour which cause significant problems for a person in relating to others. In psychotherapeutic approaches, the challenging behaviour is likely to be read as a symptom of underlying interpersonal and intrapersonal difficulties. The function it plays in a person's life and relationships provides a key to understanding his or her psychological difficulties.

10.13 Assessing Risk

The psychologist must continue to assess the risks that the challenging behaviour may present to the person showing the behaviour and other people.

Level of evidence to support this guideline: 3
Good practice
This guideline is based on current clinical consensus rather than the literature on effectiveness.
Most NHS Trusts have developed their own methods of assessing risk, with which psychologists must comply.

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11. Detailed guidelines – Formulation

11.1 Formulation

Definition: Formulation is best regarded as a hypothesis (or set of interconnected hypotheses) about the nature of the clinical problem and its development. It usually contains informed guesses about causal or functional relationships between variables/events and the central problem. It has two main functions: (a) it tells you what to do, i.e. guides your clinical action within an explicit rationale, and (b) it helps you set up criteria for evaluation of your intervention.[399]

The formulation of a clinical problem is taught on clinical psychology training courses as an essential element of the process of psychological interventions for a whole range of problems. The DCP's *Core purpose and philosophy of the profession* highlights 'formulation' as one of the four core skills of a clinical psychologist.[400] The dangers of trying to intervene without having a clear enough understanding of what is happening are seen as self evident, and there are no studies that compare interventions with and without formulation. The nearest thing to this in the field of interventions for challenging behaviour would be the meta-analytic studies which have demonstrated that positive outcome is correlated with the carrying out of a functional analysis.[401,402] In the traditional behaviour analytic model, identifying the function of a behaviour is the formulation.

It is essential that a thorough and comprehensive assessment guides the development of a formulation. The formulation should gather together the relevant information from a variety of sources, clarify the central issues and provide a starting point for intervention. The formulation is more than a mere summary of the facts. Information should be prioritised and integrated using an appropriate theoretical model, research evidence-base and clinical experience.[403 404 405 406]

There is, therefore, strong (level 1) evidence to support the carrying out of a functional analysis in interventions for challenging behaviour.

Where psychologists may be considering an individual (psychotherapeutic or cognitive behavioural) approach, it would also be seen as good practice to formulate the nature of the problem and the intervention plan.

If an organisational intervention is being considered, the organisation, its strengths and difficulties and a proposed plan for organisational change needs to be formulated using techniques from management studies and organisational psychology. There is no one single 'correct' way to carry out a formulation. How this will be presented will depend upon the context and particular purpose of the formulation.[407]

A formulation should be seen as a working model or map, which can be changed as new evidence emerges to disconfirm it, as the intervention moves along. Formulations are often useful within the multidisciplinary team as a way of helping to co-ordinate and organise thinking and understanding about the individual and how they interact with the wider system.

11.2 Integrating different factors into a formulation

The formulation should include an understanding of the onset and reasons for the development of the challenging behaviour.

It should identify personal, environmental and interpersonal factors which have increased or maintained the challenging behaviour, and also factors which prevent or reduce its occurrence.

It should present a hypothesis, which can be tested through interventions or further assessment, about the function or meaning of the behaviour for the person in his or her environment.

The psychological formulation should integrate the three basic elements of the person, the environment and the behaviour into a coherent and dynamic whole.

Level of evidence to support this guideline: 3
Good practice
If the formulation is to be inclusive, and to make sense to people living or working with the person who is challenging, then it needs to consider all the above factors. The psychologist needs to look for changes in the challenging behaviour – whether this is the onset or fluctuations in the severity or frequency of the behaviour. By seeing how the behaviour changes, and what other factors are associated with those changes, the psychologist can make a hypothesis or series of hypotheses about the behaviour and how it might be reduced.

The formulation is the stage at which the relative contributions of individual factors, environmental factors and the behaviour itself can be brought together and integrated with each other. The aim should be to reach an inclusive and coherent understanding of the challenging behaviour and the different contributions of biological, learned, interpersonal and organisational or systemic factors.

Although there is compelling evidence that both behavioural and biological processes may be involved in the development and maintenance of challenging behaviour, formulations have frequently been drawn up within, rather than across these different frameworks. Psychologists should be aiming to integrate different models within the formulation. There is a growing literature on integrating cultural, social, behavioural and biological processes into formulations.[408 409 410 411]

Models that integrate behavioural and biological mechanisms are becoming increasingly sophisticated and there are clear benefits of developing a multi-disciplinary approach to formulation.[412 413 414]

11.3 Intervention plan

The formulation should indicate a proposed intervention, making clear the reasons for the choice of a particular strategy or treatment approach. This should apply with a systemic or organisational intervention, just as much as with an approach which focuses on individual change. It should clearly indicate the target for intervention and will usually involve a multi-component plan to bring about change.

Selection of a target for intervention should be based on the following criteria:

- **capacity to change and motivation of the person with learning disabilities;**
- **the area of greatest clinical need;**
- **evidence on effectiveness of different possible interventions;**
- **skills and the people in his or her immediate environment.**

Level of evidence to support this guideline: 3
Good practice

An essential component of the psychological formulation is the plan for an intervention. The intervention should follow on seamlessly from the formulation of the problem. Consideration will need to be given to:

a) Identifying the area of greatest clinical need
A detailed risk assessment should be carried out in order to help to prioritise potential targets. Clinical need in the person with learning disabilities should be assessed by:

- interview of the person and carers;
- observation;
- data collected from records.

Factors to be assessed include:

- physical or mental ill health
- pain;
- injury or risk of injury;
- distress;
- blocks to further development;
- blocks to participation in a valued life/social inclusion.

The same needs of carers must also be considered.

Where there is conflict between the needs of a person with a learning disability and a carer, the needs of the person with learning disabilities are paramount. Every effort should be made to resolve such a conflict in a way that is acceptable to both parties – a conflict between a person with learning disabilities and those closest to him or her can be highly distressing to both.

b) Evidence of effectiveness
Where challenging behaviour is the major clinical problem, the evidence is that an applied behaviour analytic approach

is likely to be effective and should be the intervention of first choice.[415 416 417]

There is growing evidence to indicate that this approach needs to be interpreted broadly and should include the cognitions and emotional responses of people with learning disabilities, families and carers as well as strictly observable behaviour in the traditional behavioural sense.[418]

An applied behavioural analytic approach requires the focus of change to be in the systems and services which support the person with challenging behaviour, so that they can meet the person's needs more effectively.

Where challenging behaviour is seen as related to other problems which require intervention in their own right (e.g. mental health problems, psychological distress, lack of opportunities to communicate, living in a damaging or deprived environment) these problems need to be addressed, either by the psychologist or by referral to the more appropriate member of the multidisciplinary team. These underlying problems would then be the primary target for intervention. The evidence for the effectiveness of approaches which address these problems is beyond the scope of these guidelines, but has been covered within the AAMR Expert Consensus Panel for Mental Retardation.[419]

c) Skills, capacity to change and motivation of the person with learning disabilities and the people in his or her immediate environment

Choice of an intervention plan must depend on an assessment of its likelihood of successful implementation. There must be a 'goodness of fit'[420] between the intervention and those who need to be involved in its implementation. Preliminary work may need to be done (e.g. providing staff training; teaching a person with learning disabilities a self-monitoring technique) before certain interventions are feasible.

During the development and consultation process of these guidelines, there was considerable debate concerning the level of psychology input that should be provided into different settings. The experience of many psychologists is that despite intensive inputs, some organisations have such limitations that there may be only a limited impact on outcomes. This presents an ethical dilemma as to whether further input is justified. There was generally more confidence in being able to work effectively in situations where there was a skills deficit which could be remedied, than in situations where there was a problem of motivation. There are reports of successful skills training in the literature[421 422 423] but few of changing staff morale. Although studies have shown that there is an association between challenging behaviours and staff psychological well-being[424 425 426] there is only limited evidence of the effectiveness of intervening to change staff caring strategies in this area of work.[427 428]

What this guideline indicates is that a psychologist must take a hard and non-blaming look at the capacities both of the person with learning disabilities and the staff or family members around him or her.[429] It may be helpful to start with the intervention which would be indicated on grounds of effectiveness and ethics and see what is required to implement it. If possible, the psychologist should discuss the requirements with family members at home or service managers and get their views on its feasibility.

The psychologist must also consider his or her own skills and capacities in the situation. The British Psychological Society[430] is clear that psychologists must not work beyond their capabilities, while being responsible for maintaining and developing their professional skills to the best of their abilities.

11.4 Format of formulation

The psychological formulation must always be written down for future reference. It should be anticipated that it will be revised and extended after further assessment or intervention. The formulation may be presented as a flow-chart or described in ordinary paragraphs. It should be presented in a way that can be readily understood.

Level of evidence to support this guideline: 3
Good practice

Clinicians have found that a formulation can be lost sight of, if it is not written down and kept readily accessible. Given the persistence of much challenging behaviour,[431 432 433] and the fact that there can be a high turnover of staff in many services where people are challenging,[434] it is good practice to make sure that the details of the formulation and the basis on which it was developed are kept and not lost.

In the best services, formulations will not be seen as fixed and static, but as working theories which can be extended or revised as further information becomes available.[435,436]

Equally, formulations should be presented in a way which people who need to work with the client can understand. Often this will be in a visual format, and will enable the psychologist to develop a comprehensive package of intervention.

11.5 Process for developing the formulation

The psychological formulation should be the outcome of a collaborative process. This will often include the input of other clinicians.

The person with learning disabilities and anyone who is likely to be involved in the intervention must be involved in the development of the formulation.

Level of evidence to support this guideline: 3
Good practice

If steps are not taken to include the person with learning disabilities and people living and working with him or her, there is a serious risk the formulation will not be practical or socially valid. It will not fit its purpose of providing an agreed sense of direction and a shared understanding of the nature of the problem being addressed.

There is a growing research literature which focuses on the beliefs of care staff about challenging behaviour.[437 438 439 440 441] Ideas derived from common sense notions of 'bad behaviour', or from staff experience of parenting will tend to be applied, especially in the absence of alternative explanations. Sometimes this leads to staff or families inadvertently reinforcing the very behaviours they find most challenging.[442 443]

An essential part of the formulation is the creation of a shared understanding of the behaviour and how it needs to be worked with.[444]

Many clinicians have found problems of implementation in working with staff and challenging behaviour. If the process of formulation is shared, then practical problems caused by resources and skills available should be identified – and hopefully overcome – before the intervention stage. This can substantially reduce frustration and mutual blame.

Similarly, it is important ethically and practically to involve the person who is challenging services as much as possible in the process of formulation. Particularly where a proposed intervention is focused on individual change (e.g. with anger management) the person concerned needs to feel motivated and empowered by the formulation. Techniques such as self-monitoring have been used successfully with some people with learning disabilities to facilitate their involvement.

There is another practical reason for involving others in a shared formulation. It is likely to be better – more inclusive and more comprehensive. If colleagues from other professions, families and care staff are not involved in developing the formulation, it risks being impoverished. There are a number of examples of interdisciplinary assessments leading to formulations and intervention plans that combine neurobiological and behavioural processes.[445 446]

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12. Detailed guidelines – Intervention

12.1 Intervention

Definition: Psychological interventions are defined as attempts to make changes in people, their behaviour, the systems around them or their interpersonal relationships, using methods derived from a psychological knowledge and understanding of individuals and their world.

These guidelines refer specifically to interventions where the primary focus is on challenging behaviour.

Interventions for challenging behaviour can be divided into two groups:

1. Reactive behaviour management strategies
These are interventions which focus on containing behaviour which presents a risk of harm or injury to the person or others, at the time when that behaviour occurs or seems about to occur.[447]

2. Proactive prevention and treatment strategies
These strategies focus on the prevention, reduction or elimination of challenging behaviour through planned interventions.[448] [449]

The guidelines for interventions for challenging behaviour are presented in three sections:

- ethical issues and priorities;
- reactive behaviour management strategies;
- proactive strategies.

12.2 Ethical issues and priorities

Managing risk

Where aggression or self-injurious behaviour presents a serious risk to the person who is challenging or others, effective and ethical reactive strategies for managing the behaviour as it happens or seems about to happen need to be in place as a matter of urgency. At minimum, the psychologist has the responsibility to check that such a strategy is in place and that it is being used ethically.

Duty of care to provide effective interventions

There is an obligation on the psychologist working with behaviour which presents a severe risk to the person or others to use his or her skills and knowledge to provide the most effective interventions, available in order to reduce the incidence and severity of the challenging behaviour.

Prevention of abuse

No interventions for challenging behaviour should be abusive. A psychologist must not use interventions which constitute 'cruel, inhuman or degrading treatment or punishment'.[450]
Psychologists have a duty to report colleagues (of whatever discipline) who are using such interventions, in order to prevent their use.

Where the assessment indicates that challenging behaviour is likely to be a response to a neglectful or abusive environment or relationship, the psychologist has a primary duty of care to the welfare of the person with learning disabilities. The psychological intervention should endeavour to protect the person with learning disabilities by changing the environment or relationship rather than stop the behaviour and thereby silence the person's protest.

When abuse is suspected, local policies (e.g. on abuse of children or adults; on quality of care) and the BPS Code of Conduct must be consulted and followed. Psychologists must consult with experienced colleagues especially if they are in any doubt as to what course of action to take.

Level of evidence to support these guidelines: 3
Essential practice

These guidelines have been informed by the discussions held at the clinicians' conference in January 1997, and by feedback and further discussions during the consultation process. They are not based on evidence for effectiveness but on the views of experienced clinicians supported by

reference to the British Psychological Society *Professional Practice Guidelines*[451] and *Code of Conduct*.[452]

Guidelines on reactive strategies

These guidelines need to be considered in the light of local and national guidelines, policies and procedures on managing violence and aggression. Each clinical psychology department should ensure that such policies are being implemented in the places where they work.

National guidelines,[453] [454] [455] [456] have been developed which provide a clear framework for staff who work in situations in which the implementation of physical interventions may be considered.[457]

12.3 An individual approach to reactive strategies

An effective and ethical reactive strategy for managing challenging or potentially dangerous or offensive behaviour needs to be based on an understanding of the individual and devised on a case-by-case basis.

The information collected through functional assessment should be used to guide the choice of a strategy.

Where there is a need to have a strategy in place quickly because of a high and immediate risk of harm to the person or others, hypotheses about the function of the behaviour should be collected from people (families or staff) who know the person well and from records. These should be used to guide the choice of a strategy.

Level of evidence to support this guideline: 3
Good practice

Because of the different functions of challenging behaviour, a reactive strategy which is effective for one person will not necessarily be effective for another. For example, one person may start to self injure in an attempt to engage staff in dialogue, whereas another person may show the same behaviour in order to be left alone or be taken to a 'quiet room' away from interaction with other people. In this case, different strategies will be necessary for the immediate management of the self-injury as well as a longer-term intervention strategy. Psychologists must avoid using reactive strategies which will reinforce the challenging behaviour in the longer term. It is possible for self-injurious behaviour to increase in response to staff and family reactions to the behaviour.[458] Similarly, psychologists should not support the use of reactive procedures that could potentially act as punitive stimuli for service users (e.g. via the infliction of physical pain) or as a vehicle for retribution.

The results of functional analyses can also be used to directly inform reactive management plans[459] in that they should generate data on:

- the specific forms of challenging behaviour that need to be considered;
- how these behaviours may link together in a behavioural chain;
- their frequency, intensity and duration;
- their historical and current triggers;
- the individuals at risk;
- the escalatory pattern of the challenging behaviours;
- immediate indicators that the behaviours are about to occur.

There has been some debate among psychologists about the possible conflict between the need to act quickly to reduce the risk of harm caused by challenging behaviour and the need to assess thoroughly enough to ensure that the strategy selected will be effective. Doing nothing until a full assessment is completed may carry too high a risk of injury caused either directly by the person with challenging behaviour or by staff or families resorting to dangerous physical interventions, for example, when attempting to prevent injury. When formal advice is not provided, carers will tend to devise their own responses. In a study of 5- to 18-year-olds[460] who displayed high rates of aggressive behaviour, physical interventions were already in place for 56 per cent of the children at the time of referral to a specialist support service. These interventions had been improvised by carers.

In the absence of safe, effective procedures for responding to high-risk behaviours, the chances of carers implementing or maintaining positive behaviour change strategies are significantly reduced[461] and the potential for service user abuse is significantly increased.[462] [463] There is limited evidence to suggest that the provision of training in reactive management may be a key variable in sustaining placements for severely challenging individuals[464] [465] and in reducing the use of anti-psychotic medication.[466]

It may, therefore, sometimes be necessary to introduce reactive procedures in advance of detailed functional analyses or behaviour change strategies being in place; in such circumstances, appropriate analyses or interventions must be initiated in parallel to the reactive procedures.

In all cases, the risk of using an inappropriate reactive behaviour management strategy must be weighed against the risks of harm or injury arising from the challenging behaviour itself.

Where the risk is high, and a strategy needs to be implemented quickly, it will be particularly important to monitor the effects of the strategy in practice. Procedures should be reviewed and changed if they are seen to be having a deleterious effect on the person with learning disabilities or others.

12.4 Purpose and limitations of reactive strategies

The focus of reactive strategies should be to ensure the safety of the person who is challenging, other people with learning disabilities, staff, family members and any bystanders.

Reactive strategies are therefore concerned only with managing difficult episodes of behaviour; they are not designed to produce long-term changes in behaviour.[467] For this reason, reactive strategies should not be used in isolation, but must be embedded within a broader programme of interventions designed to produce behavioural change.

Written reactive management plans should be in place for all service users whose behaviour poses risk to the person themselves, their carers or members of the public.

Reactive management plans must always co-exist alongside positive strategies for achieving behaviour change.

Level of evidence to support this guideline: 3
Essential practice

Local policies on managing violence and other challenging behaviours should contain a statement about the primary purpose of any techniques used.

12.5 Selecting a reactive strategy

Reactive strategies should follow the principle of least intrusiveness and least restrictiveness. A reactive plan should offer advice on responding to lower levels of challenging behaviour in ways that may help to defuse further behavioural escalation as well as guidance on responding to severe behavioural outbursts.

Strategies that are restrictive or intrusive (e.g. physical interventions) should only be used in conjunction with a written service policy and be carefully monitored and reviewed.

The severity of risk presented to the person or others should be considered when deciding on an appropriate reactive strategy.

Non-physical reactive strategies which may be effective include:

- **not responding to challenging behaviours;[468]**
- **at the same time attempting to cue in or reinforce alternative more positive behaviours;[469]**
- **removing demands;[469]**
- **diversion to a reinforcing or compelling event or activity;[468]**
- **strategic capitulation;[468]**
- **low arousal approaches where others stay calm, quiet and non-threatening (e.g. by maintaining appropriate interpersonal space) and try to avoid escalating arousal and the risk of physical violence.[470 471]**

Only when these approaches have proved ineffective, and where the behaviour presents a serious risk to the person or others, should the planned and well-monitored use of physical intervention procedures be considered. These should contain the challenging behaviour while avoiding injury to the person or others. It is recommended that if physical interventions are required, they should:

- **be appropriate to the needs of children and adults with intellectual disabilities**
- **be used for the shortest time possible**
- **employ the minimum reasonable force**
- **not inflict pain**
- **not impede the process of breathing**

- **avoid vulnerable parts of the body e.g. neck, chest and sexual areas**
- **avoid hypertension, hyperflexion and pressure on or across joints**
- **not employ potential dangerous restraint holds**
- **avoid unsupervised modifications to taught strategies**

Level of evidence to support this guideline: 3
Good practice

These guidelines are derived from clinical views of good practice, informed by ethical considerations; there is an urgent need for a systematic review of the effectiveness of different reactive strategies.[472 473]

It is recommended that local policies are used to inform good practice in the field of reactive strategies for challenging behaviour. Local management groups or ethical committees should review reactive behaviour management strategies. There is some evidence to suggest that where there is no guidance, staff are left having to make rapid decisions at a time when they may feel highly stressed, angry or afraid – conditions under which poor practice, abuse or injury are more likely to occur.[474 475]

12.6 Recording and review of reactive strategies

All reactive strategies for managing challenging behaviour must be written down and in a format and location that is readily accessible. They must be updated and reviewed regularly and frequently. Their use must be recorded and monitored.

Level of evidence to support this guideline: 3
Good practice

This guideline is based on the clinical consensus on good practice, supported by the published guidelines on managing challenging behaviour.[476] Sample formats for reviewing reactive strategy usage are available.[477]

12.7 Training in the use of reactive strategies

Everyone who is likely to use the reactive strategy (including the psychologist) should receive training which includes opportunities to practice implementing the strategy. This training must be updated on a regular basis while the strategy is in place. Training should always include both preventative and reactive components.[479]

Level of evidence to support this guideline: 2
Good practice

There is evidence of a need to include reactive behavioural training for carers as part of an overall intervention package. While there is some evidence to suggest that such training can have beneficial effects, outcomes can be highly variable, and the overall quantity and quality of research in this area is poor.[479] Positive results reported to date include improved carer knowledge and confidence; enhanced competence in physical intervention skills; and reduced rates of challenging behaviour and physical interventions. Minimal or negative results have also been reported in each of these areas. It has been suggested that training in physical interventions will be enhanced if skills are taught one at a time and subject to repeated practice,[480] and that acquired skills will fade if there is no opportunity to practice.[481]

Guidelines on proactive strategies

12.8 The context of interventions

Interventions, which aim to reduce or eliminate challenging behaviour, should be implemented in the context of a positive environment with programmes in place for the person's development and enhanced quality of life.

Level of evidence to support this guideline: 3
Good practice

There is a risk that interventions may be used to ensure that a person conforms to an unacceptable or damaging environment. This is not an ethical use of psychological techniques. In order to prevent this happening, the psychologist should ensure that the person's needs are being addressed in a positive way and that reducing the challenging behaviour is not the sole focus of concern.

12.9 Service policies and procedures

It is recommended that local guidelines or policies should be in place for the use of controversial or restrictive procedures, that staff should receive adequate training in any such policies and that there should also be access to an ethical committee or similar support for the consideration of difficult cases.

Level of evidence to support this guideline: 3
Good practice

Many services have position statements about the use of restrictive or potentially aversive procedures. We would commend this practice. However, it is extremely important that staff understand both what is meant by the term 'aversive' and what is or is not aversive for people on an individual basis.

Any policy on the use of restrictive or aversive procedures, including policies which say such procedures are unacceptable, must be backed up with comprehensive training for existing staff and for new staff as they are inducted. Staff are likely to revert to parental or 'common sense' models of coping with challenging behaviour – including 'telling them off' or 'not letting them get away with it' – if they are not trained in alternative approaches and supported in their use.

12.10 Considerations in service interventions

Changing aspects of the environment in which the person is supported is often a central component of intervention strategies. Interventions which aim to change environmental factors in a service setting include:

- **consultancy and advice;**
- **staff training;**
- **supporting staff and managers in organisational change processes.**

It is recommended that in a service setting, a written contract is made with managers and staff groups. The contract should:

- **define the target for intervention**
- **indicate the plan of action**
- **make clear what is expected from staff and the psychologist.**

The contract must be monitored and reviewed.

In a family, there should also be clarity about the target for change and what is expected of the psychologist and of family members.

Level of evidence to support this guideline: 2
Good practice

It is important that there is clarity about the relative roles of the psychologist and a service manager in instituting and sustaining organisational change. Experience from small houses for people with challenging behaviour has shown the importance of management commitment to creating and maintaining a positive environment and provides an indication of the type of supportive role which a psychologist might play.[482] [483] [484]

12.11 Selecting a proactive strategy

The intervention strategy should focus on the chosen target for change. It should follow on logically from the functional assessment. Strategies that prevent the challenging behaviour should be considered first.

Choice of strategy should be based on the following criteria:

- **known effectiveness in reducing or preventing challenging behaviour;**
- **other benefits for the person with learning disabilities;**
- **capacity for long-term maintenance;**
- **capacity for generalisation;**
- **ethical considerations;**
- **social validity – acceptability to families, staff, the general public;**
- **ease of use or application.**

Level of evidence for this guideline: 3
Good practice

This guideline is based on clinical consensus on good practice.

Proactive strategies may focus on the person, the behaviour or the environment as the target for change. The locus of intervention may be before the challenging behaviour occurs, while it is happening, or after it has happened. It is self evident that preventing the behaviour from starting in the first place is more desirable than responding to it after it has happened.

Potential approaches to prevention which focus on the *person* include:

- altering the person's bio-behavioural state
- cognitively-based interventions for psychosocial problems
- developing the person's capacity to cope with potentially stressful events or to communicate more effectively

Preventative approaches which focus on the *behaviour* include:

- changing the nature of preceding activities;
- changing the nature of current activities;
- differential reinforcement

Preventative approaches which aim to change the *environment* include:

- introducing a range of positive environmental changes;
- increasing the person's choice and control.

Approaches where different responses to the challenging behaviour are systematically introduced include extinction and punishment. The preceding preventative strategies should be considered before these, and in preference to them.

12.12 Altering the person's bio-behavioural state

Where the assessment has indicated that bio-behavioural factors in the individual are related to challenging behaviour, these need to be addressed.

Referrals should be made to the appropriate clinician if medical or other problems are suspected.

Participation in physical exercise has also been shown to reduce challenging behaviour.

Level of evidence to support this guideline: 2
Good practice

There is some evidence from case studies for the effectiveness of altering bio-behavoural states through addressing illness, pain or discomforst, and by increasing physical activity.

A range of bio-behavioural states have been shown to be correlated with the occurrence of challenging behaviour. These include such factors as alertness, fatigue, sleep/wake patterns, hormonal changes, drug effects, seizure activity, psychiatric disorders, mood and illness or pain.[485] Examples of this are menstrual pain linked with aggression[486], otitis media making ambient noise aversive and leading to self injury.[487] Approaches to intervention include the treatment of sleep disorders,[488 489 490 491 492] appropriate treatment of medical conditions[493 494] and changes to medication regimes.[495]

Suspected medical factors should be brought to the attention of the appropriate doctor. As well as the obvious benefit of treating illness or pain, a reduction in the challenging behaviour may also be the outcome.

Numerous studies have reported that physical exercise may result in reductions in stereotypic,[496 497 498 499 500] self-injurious, [501 502] aggressive or disruptive behaviours.[503 504 505 506] Greater reductions in challenging behaviour have been reported for more strenuous activities (e.g. jogging compared with ball games).[507] The accumulated evidence points to a consistent, although not inevitable, short-term effect of aerobic exercise on subsequent activity. [508]

12.13 Cognitively-based interventions for psychological problems

When challenging behaviour appears to be a response to a person's psychological distress or a mental health problem, this needs to be treated by the most effective means possible.

Psychological problems such as anxiety, phobias and depression can be treated effectively with cognitive behaviour therapy in people with learning disabilities who have the motivation and skills necessary for cognitive techniques.

Level of evidence for this guideline: 2
Good practice

Where early experience or previous neglect or trauma is thought to have led to current challenging behaviour, psychotherapy, cognitive behaviour therapy or counselling should be considered. These approaches have been demonstrated to be effective for people without a learning disability.[509]

People should not be excluded from effective therapeutic approaches because they have a learning disability; their capacity to benefit must be assessed on a case-by-case basis.

Suggested factors to consider include:[510]

- verbal communication skills;
- cognitive skills (e.g. autobiographical memory; capacity to reflect on inner experiences; capacity to understand metaphor);
- capacity to tolerate distressing emotional states;

- suggestibility and assertiveness;
- capacity for interpersonal relationships.

Current environmental factors must be assessed as well as the person's intrapsychic or interpersonal strengths and difficulties; the environment needs to be able to support a person who is in psychotherapy and may experience distress and intrusive memories as a result.

There is a growing literature demonstrating that cognitive behavioural approaches can be effective with people with learning disabilities.[511] [512] [513] [514]

There is a very small body of literature concerning the provision of psychotherapy for people with intellectual disabilities.[515] [516] [517] The majority of reports are case reports, and as yet there are no controlled studies. A number of studies report on the outcome of psychodynamic psychotherapy with adults who have a learning disability and co-morbid mental health problems [518] [519] or have offended.[520] [521]

The person's environment will need to be assessed as well as the individual's ability to make use of cognitive behavioural approaches. Families or services need to be able to reinforce new skills and attitudes developed by cognitive-behaviour therapy.

Where a group rather than an individual approach is indicated, the person's ability to tolerate being in a group, to express themselves in a group setting and to listen appropriately to others should also be considered. Again, there is evidence from research with non-learning disabled people that group approaches can be effective – this needs wider and more systematic replication with learning disabled groups. A few accounts of therapeutic groups with people with people with learning disabilities exist, but there is little evidence to support their effectiveness.[522]

12.14 Developing the person's capacity to cope with potentially stressful events, or to communicate effectively, through psycho-educational approaches or skills training.

Where challenging behaviour appears to be a response to stressors In the environment, people with learning disabilities can be taught alternative ways of coping or problem solving. Anger management techniques can also be learnt.

Where challenging behaviour has a communicative function, functional communication training can be of benefit.

Level of evidence for this guideline: 2
Good practice

There is a substantial body of literature on effective ways of teaching skills to people with even the most severe learning disabilities.[523] [524] There is an extensive literature too on teaching new skills to people with learning disabilities and challenging behaviour.[525] [526] [527]

A review of 16 published reports on interventions based upon anger management approaches[528] suggests that intervention packages can be effective, but the differential effectiveness of the components has not been established.[529]

12.15 Principles of functional equivalence

Behavioural interventions are most likely to be both effective and ethical if they follow the principle of functional equivalence. Once the function of the behaviour has been identified through functional assessment, the challenging behaviour can be replaced with a functionally equivalent but more positive behaviour. This, in effect, enables the person to exercise control over important aspects of their day to day life, without resorting to challenging behaviour.

Level of evidence to support this guideline: 1
Essential practice

This guideline is based on clinical views of ethical practice, supported by the literature which indicates the importance of carrying out a functional analysis (see *Guideline 10.12*), and on the evidence for effectiveness of intervention techniques that are based on the idea of functional displacement (e.g. functional communication training).

Functional displacement: Intervention through functional displacement seeks to introduce a new behaviour (or increase the rate of a pre-existing behaviour) which will tap in to the existing contingencies of reinforcement and displace the challenging behaviour.[530] [531] [532] [533] A number of

studies have demonstrated the viability of the procedure across a number of settings, participants and challenging behaviours.[534–562] In addition, studies have indicated that the treatment gains achieved may generalise across settings and therapists[563 564] and may be maintained over time.[565 566] Functional displacement will only be effective if the replacement response is equivalent to the challenging behaviour and is also a relatively more 'efficient' response.[567] Response efficiency is a complex construct reflecting the combined effects of response effort and the rate, delay and quality of reinforcement contingent upon the response. As a result, in order to maximise the impact of intervention, it may be important to increase the response efficiency of the replacement behaviour and decrease the response efficiency of the challenging behaviour. That is, it is likely to be necessary to combine functional displacement or functional communication training with more traditional reactive strategies (e.g. extinction, time-out) to weaken the challenging behaviour.[568 569 570]

12.16 Changing the nature of preceding activities

Changing the behaviours which have been identified as leading up to challenging behaviour can reduce the likelihood of it happening to a significant extent. New activities or patterns of behaviour may be introduced, or triggers or predisposing factors may be taken away or diminished.

When the assessment has identified clear and specific triggers for serious challenging behaviour (e.g. exposure to prior activities or events) it is recommended that these triggers are removed where possible and appropriate.

Level of evidence for this guideline: 2
Good practice

The nature of preceding activities may have a significant impact on people's responses to ongoing events. Studies have examined the relationship between a variety of types of preceding activities and subsequent rates of challenging behaviour.
These include studies of the effects of:

- behavioural momentum in increasing compliance and reducing challenging behaviours associated with non-compliance;
- choice making;
- task variety and stimulus fading;
- exercise; and
- a variety of idiosyncratic establishing operations.

Behavioural momentum[571] is a phenomenon that has been applied to the reduction of challenging behaviour. Following repeated reinforcement, behaviour appears to gain a 'momentum' which makes it temporarily resistant to change. For example, preceding a request to take medication (which often led to challenging behaviour) with a series of requests to 'give me five' resulted in increased compliance and reduced challenging behaviour.[572] A number of studies since then have illustrated the viability of this procedure across a range of settings.[573 574 575 576]

Increasing task variety[577 578] (and decreasing repetition) was shown to be associated with immediate and significant reductions in aggression and tantrums, but it should be noted that one participant in these studies showed a preferance for task repetition. This highlights the need for interventions to be based on individualised functional assessments.

The use of *neutralising routines* has been shown to be an effective intervention.[579] When an activity or event has been shown likely to precede challenging behaviour (e.g. having a disturbed night's sleep, or the cancellation of an activity), a 'neutralising routine' can be introduced to compensate (e.g. an hour's nap, or taking part in another enjoyable activity). This can then prevent the challenging behaviour from occurring.

The effectiveness of physical exercise as a preceding acticity has been discussed already (Guideline 12.9).

A number of studies have presented data to link other *idiosyncratic* events (e.g., difficulty getting up, the choice of route to school) with an increased probability of challenging behaviour.[580 581] Clearly, a thorough functional assessment is essential for identifying the operation of such idiosyncratic associations.

Reducing exposure to events or activities which appear to be aversive to an individual, and so generate challenging behaviour ('triggers'), is self-evidently good practice. It is both an ethical and an effective way of reducing challenging behaviour. For example, a person may demonstrate distress and challenging behaviour in large

group settings. In such a situation it would be more ethical to help rearrange the person's activities to avoid such settings, rather than to make the person comply with routines that have been derived for the convenience of staff or organisations. In such situations a judgement needs to be made as to whether a particular necessity is driven by staff needs or the needs of a person with learning disabilities.

12.17 Re-introducing triggers

If the potential triggers for challenging behaviour need to be reintroduced because they will benefit the person with a learning disability, then a programme should be devised to introduce them carefully and positively using techniques such as embedding or stimulus fading (systematic desensitisation).

Level of evidence for this guideline: 2
Good practice

There are circumstances in which a person may be experiencing a particular event or activity as aversive but nevertheless needs to learn to cope with it as: (1) avoidance may not be practically possible; (2) the activity may be of considerable benefit in itself. There is evidence to indicate how this might be achieved. In such situations it can be effective to eliminate exposure to the activity and then gradually reintroduce it (stimulus fading) in a positive context (embedding).

'Stimulus fading'[582 583] refers to the temporary withdrawal and gradual reintroduction of stimuli which set the occasion for challenging behaviour. This technique has been combined with the use of negative extinction in the treatment of escape-motivated self-injurious behaviour. The results of these studies suggest that while stimulus fading may help avoid the occurrence of an extinction burst,[584] it does not necessarily appear to increase the effectiveness of the extinction procedure itself.[585] The technique of stimulus fading is procedurally similar to the techniques of systematic desensitisation and reinforced graded practice in the treatment of fears and phobias.[586] This suggests that the effectiveness of stimulus fading may be increased if combined with procedures incompatible with arousal (e.g., relaxation, massage, eating). While there have been no tests of this specific hypothesis, a few case studies have reported the beneficial effects of including relaxation training or massage as a component of more complex treatment packages.[587 588 589]

'Embedding' has been defined as 'a procedure that involves placing demands in a positive context, which is any situation that puts the person with disabilities in a good mood.'[590] Sometimes changing relatively superficial aspects of the context in which challenging behaviours occur can have a significant impact.[591] Similarly, a number of studies have shown that increasing the availability of positive reinforcers or preferred materials in 'high-risk' situations may significantly reduce escape-motivated challenging behaviour.[592 593 594 595] Substantial reductions in challenging behaviour and reduced negative affect (measured through ratings of facial expression) have been reported[596] when 'fast-paced' music was incorporated into situations that were associated with high rates of challenging behaviour.

12.18 Strategies for positive environmental change

There are a number of preventative strategies which focus on changing the environment. These include positive curriculum design, increasing choice, and environmental enrichment. Creating an environment which is more adapted to the person's needs and preferences can reduce challenging behaviour as well as being beneficial in its own right.

Level of evidence for this guideline: 2
Good practice

The evidence for these interventions comes from a number of studies.

Curriculum design and supported routines
Several studies have reported reductions in challenging behaviour as a result of using assessments of participant preferences to design educational or vocational curricula.[597 598 599 600 601 602 603 604 605 606 607] The results indicated significantly greater occurrence of challenging behaviours during activities that were non-functional, age-inappropriate or non-preferred. Replacing them with activities which were meaningful, appropriate and preferred led to reductions in challenging behaviour.

Increasing choice: A small number of studies have also

suggested that the actual act of choosing may be important in increasing participation[610 611 612 613] and reducing challenging behaviour.[614] It was found that when the children chose tasks they showed greater engagement and less challenging behaviour than when simply presented with identical tasks at other times, although the results of other studies should be noted.[615 616]

Environmental enrichment and non-contingent reinforcement: A number of studies have indicated that generally enriching the environment by, for example, increasing interaction with materials or introducing materials into barren environments may lead to a reduction in the rate of challenging behaviours. Thus, for example, increasing social contact,[617 618] providing toys,[619 620 621] individually preferred activities,[622 623] visual stimulation,[624] leisure activities[625] and music[626] have been associated with increased compliance,[627] reduced rates of stereotypy[617 618 621 624 626] and self-injury.[619 620 622 623] Similarly, moving from materially and socially deprived institutional settings into enriched community-based residential provision is commonly associated with a reduced rate of stereotypic (although not more seriously challenging) behaviour.[628] However, other studies have indicated that increasing the level of stimulation in the environment through visual displays,[629] television[630] and crowding[631] can lead to *increased* rates of stereotypy,[629 630] aggression[631] and decreased task performance.[629] The results suggest that for some individuals environmental enrichment may be associated with increased rates of negative reinforcement (e.g. overarousal, increased rates of negative peer contact). The contradictory nature of the results again highlights the importance of basing interventions on prior functional assessment.

Non-contingent reinforcement means increasing the background rate of the specific reinforcer maintaining the challenging behaviour. Several studies have indicated that this procedure may be effective in reducing challenging behaviour.[632 633 634 635 636 637 638 639 640 641 642 643 644 645 646] However, given the generalised importance of our ability to exercise control,[647] and the very limited opportunities for control available to people with severe disabilities, the use of non-contingent reinforcement *on its own* should be advocated with some caution.

12.19 Increasing other behaviours

It is possible to reduce the incidence of challenging behaviour by reinforcing (and thereby increasing the rate of) other behaviours. This is differential reinforcement. This strategy is more likely to succeed if the new behaviour requires less effort than the challenging behaviour, or if the reinforcers for it are more immediate and powerful.

Level of evidence for this guideline: 3
Good practice

Differential reinforcement seeks to intervene indirectly on challenging behaviour by increasing the rate of other behaviours.[648 649 650 651] These include: the *differential reinforcement of other* behaviour (DRO) and the *differential reinforcement of alternative* (DRA) or *incompatible* (DRI) behaviour. The differential reinforcement of other behaviour, also known as omission training, is a non-constructional procedure involving the delivery of a reinforcement contingent on the non-occurrence of the targeted challenging behaviour during an interval of time or, more unusually, at a specific point in time. The differential reinforcement of alternative or incompatible behaviour involves the delivery of reinforcement contingent on the occurrence of a specified alternative behaviour (DRA) or a behaviour which is physically incompatible with the challenging behaviour (DRI).

Individual studies have reported marked variability in the outcomes associated with differential reinforcement procedures, with results ranging from complete suppression, through marginal improvements to increases in the rate of challenging behaviour over baseline.[653] In general, however, it would appear that such procedures may not be particularly effective in reducing severely challenging behaviours.[654 655] An effective procedure should aim to ensure that:

1. the alternative behaviour requires less effort than the person's challenging behaviour;
2. the rate of reinforcement delivered contingent on the alternative behaviour is greater than the rate of reinforcement maintaining the challenging behaviour;
3. reinforcement is delivered immediately upon occurrence of the alternative behaviour;
4. the reinforcers selected are more powerful than those maintaining the challenging behaviour, preferably through the use of empirical procedures to identify reinforcer selection.

12.20 Directly altering the consequences of challenging behaviour

Behavioural techniques that manipulate the consequences of behaviour have often been misapplied. They are often restrictive and solely seek to eliminate challenging behaviour. As a result, they need to be used with caution. Nevertheless, there is evidence that such reactive strategies as extinction and punishment can be effective in reducing challenging behaviour.

12.20.1 Extinction

Extinction should only be considered as a treatment option in situations where the following apply:

- **in conjunction with sufficient other opportunities for positive reinforcement and not in a deprived environment**
- **in conjunction with a constructional approach (e.g. functional communication training);**
- **when the consistent application of the technique can be assured;**
- **when the possibility of an 'extinction burst' (i.e. marked increase in the behaviour before it decreases) does not hold a serious risk to the person with challenging behaviours or others;**
- **when the possibility of increased behavioural variability (as the person tries other ways of achieving his or her goals) can be contained or worked with in a constructive way.**

Level of evidence to support this guideline: I
Good practice

If the functional analysis has demonstrated that a particular behaviour seems to occur because it is being reinforced by consequences that are positive for the individual, then removing the reinforcer after the behaviour should stop the incentive for the behaviour. Extinction is the technique of taking away the reinforcer. Sometimes extinction will involve not taking away negative reinforcers. For example, if a challenging behaviour seems to have a function of enabling the person to get away from an unwanted demand (escape function), an extinction programme would stop them getting away (escape extinction).

There is strong evidence from a meta-analysis to demonstrate that extinction can be an effective intervention for challenging behaviour.[656] However, most studies were carried out under very controlled institutional conditions, thereby limiting their applicability to current practice. They also involved considerable physical risk. For example, in one successful case a child stopped self-injuring after eight treatment sessions, but during that time he hit himself 9000 times.[657]

There are three practical difficulties with applying this technique in typical community settings:
Consistency: Extinction needs to be applied very consistently by everyone with whom the person comes into contact. When behaviour is challenging, this can be very difficult for staff or families in the heat of the moment. Similarly, the responses of members of the public in a community setting cannot be controlled. Without such consistency, the behaviour will be on an intermittent reinforcement schedule, where the behaviour is sometimes reinforced and sometimes not. This tends to lead to a strengthening rather than a reduction in the target behaviour.

Extinction burst: An extinction burst refers to the temporary increase in behaviour frequency and variability during the early stages of the extinction process. This creates obvious risks with aggressive or self-injurious behaviour.

Environments with few reinforcers: There is an obvious ethical problem associated with withholding reinforcing activities, especially when a person may have little access to sources of reinforcement. When people live in impoverished conditions, extinction should be only used with extreme caution.

Extinction should therefore not be used on its own without another constructional programme such as skills training or a non-contingent increase in access to other reinforcing items or activities. There is some evidence to support the effectiveness of such a combined approach.[658]

If staff or families are to use extinction as a technique, the psychologist must ensure that they are familiar with the technique, happy to use it and can apply it consistently and when under pressure. Staff in community settings report difficulties of feeling 'on show'[659] which mean that programmes where they are asked not to respond to a challenging behaviour can be particularly difficult to implement in public settings.

12.20.2 Punishment

There are many clear ethical objections to the use of punishment as a technique and many services expressly forbid the use of any aversive techniques, in which case punishment can never be used.

It is important to be clear about the idiosyncratic nature of aversives and recognise that responses that may be pleasurable and reinforcing to some people (e.g. physical contact), may be aversive to others, and vice versa. The psychologist needs to consider whether the use of teaching techniques or other strategies might constitute aversive approaches. For services which allow the use of aversive techniques in limited and controlled circumstances, the following guidelines are suggested:

- **punishment must never be used as a sole intervention strategy, without additional measures being taken to ensure a high standard of care, individualised plan for the person's development and improved quality of life;**
- **there are some punishment strategies which should never be used because they constitute 'cruel and unusual treatment'. Examples of this would include painful electric shock, beatings and other assaults on the person;**
- **punishment must only be considered as an intervention where the challenging behaviour presents a serious risk to the person or others;**
- **it should never be used without a detailed functional analysis and a review of all other treatment options, including a critical review of previous intervention attempts;**
- **a decision as to whether or not it should be used should not be taken by an individual. The use of punishment should always be referred to a service ethical committee or similar review body which has multidisciplinary and informed lay membership;**
- **every effort should be made to obtain the person's informed and free consent to the procedure. If this is not possible, the views of an independent advocate for the person with learning disabilities should be sought prior to treatment. Consideration should be given to the question of whether the same technique would be applied to a person without a learning disability in similar circumstances.**
- **if punishment is agreed to be appropriate under these constraints, then its use must be reviewed and monitored closely:**
  - **every instance of its use must be monitored in writing;**
  - **possible effects of punishment on the individual must also be monitored (e.g. signs of distress, social withdrawal);**
  - **there must be frequent reviews of its use;**
  - **a date should be set at the outset for a major review, at which the use of punishment would be discontinued unless there was very strong evidence to support its continuation;**
  - **the client (or independent advocate) should have the right to appeal (to an independent authority and not those responsible for carrying out the technique) against the use of punishment at any time.**
- **Where the psychologist witnesses or has reported to him or her the informal use of a punishment strategy, they must challenge its use and follow the local child or adult abuse procedures and report the incident to the appropriate person.**

Level of evidence to support this guideline: I
Essential practice

Definition: Punishment is defined as the application of a response which is aversive to the individual immediately after the target challenging behaviour has occurred. Punishment may be 'positive' (in the technical sense of adding a stimulus). Examples would include telling the person 'No' or scolding them, causing physical pain or discomfort or psychological distress. Alternatively it may be 'negative' (in the technical sense of taking away a stimulus) – taking away something reinforcing (e.g. time out; screening one's face to prevent visual contact). It needs to be distinguished from giving feedback or information to the person about their behaviour (e.g. saying 'No, that is hurting.' in a calm and quiet manner).

Punishment has been demonstrated to be effective in the meta-analyses[660] [661] although this has been strongly contested because of the ethical unacceptability of many of the studies. Several writers give a flavour of this debate.[662] [663] [664] Most of these studies were carried out under very controlled institutional conditions, thereby limiting their applicability to current practice. They also tended to use highly aversive or abusive procedures (such as contingent powerful electric shock) which would never be acceptable under current circumstances. There are, however, studies that report effective interventions using 'mild' punishment strategies (e.g. visual screening, verbal reprimand).[665]

Given the ethical considerations and the availability of other interventions that are effective without being aversive, there should be very little need to use punishment.

References: Section 12

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13. Detailed guidelines – Evaluation

13.1 Evaluation

Definition: Evaluation is the measurement of change in order to determine the impact or effectiveness of interventions.

13.2 Evaluation of effectiveness

Interventions for severe challenging behaviour should be routinely evaluated for their effectiveness.

Level of evidence to support this guideline: I
Good practice

It is accepted by clinicians that evaluating the effectiveness of interventions for challenging behaviour should be routine good practice.

There is also evidence from the meta-analyses to suggest that those studies that are more thoroughly evaluated are more likely to demonstrate a positive outcome.[666] [667]

13.3 Content of evaluation

As a minimum, the evaluation should consider

- **the severity, frequency and duration of the target challenging behaviour;**
- **the person's quality of life and range of activities or opportunities;**
- **the person's development of positive skills and abilities;**
- **the person's well-being and satisfaction with the intervention;**
- **the well-being and satisfaction of carers or family members in close contact with the person.**

An evaluation will usually repeat baseline measures from the start of an intervention and look for any evidence of change.

Level of evidence to support this guideline: 3
Good practice

When a person is referred to a psychologist because of challenging behaviour, the psychologist must measure the impact of any intervention on that behaviour. This is an ethical obligation because the nature of challenging behaviour is such that by definition there is a threat to the health and well being of the person concerned or those close to him or her.

Measuring challenging behaviour alone, however, is seen by many clinicians as an excessively narrow focus. Successful outcome can also be measured by increased quality of life and enhanced well being of the person who is challenging and that of other people in the person's life. These factors, which are threatened by the existence of the challenging behaviour, should therefore also be measured.

For guidance on methods that can be used to evaluate the effectiveness of interventions for challenging behaviour, see the extensive discussions in the guidelines on assessment above (Section 10).

13.4 Evaluation of the specific intervention

The evaluation should measure the impact of a specific intervention. For example, interventions that are focused on environmental change should evaluate the success in achieving environmental targets, whereas anger management techniques should measure the reduction in anger.

Level of evidence to support this guideline: 3
Good practice

The psychologist needs to make a specific evaluation of those factors that he or she is attempting to change. If an intervention attempts to teach new skills, for example, then the acquisition of those new skills should be measured. If the intervention is hoping to change an environment, then measures of the environment need to be taken before and after the intervention.

It is particularly important to measure the effectiveness of new or relatively under-researched interventions, and to disseminate the results.

13.5 Follow-up evaluation

The effectiveness of the intervention should be measured over a period of time.

It is recommended that the outcome should be re-assessed after one year if an intervention is completed.

If the intervention is ongoing, then its impact should be re-assessed regularly, at least on an annual basis and more often if necessary.

Level of evidence to support this guideline: 3
Good practice

There is now considerable evidence to suggest that challenging behaviours can be highly persistent over long periods of time. As a result, it is essential that progress is monitored repeatedly over extended time periods. This allows for (1) measurement of the impact of interventions; and (2) the early identification of potential deterioration or relapse.

Work on relapse prevention with people with learning disabilities is at a very early stage. The literature however, indicates that relapse is a very real problem: 'patterns of severe challenging behaviour do not simply disappear'.[668]

In a study of 179 people,[669] it is reported that 63 per cent of them who were identified as showing 'more demanding' challenging behaviour in a total population survey undertaken in 1987, were still showing 'more demanding' challenging behaviour when followed up seven years later. Persistence rates of over 80 per cent over a 10 year period for many categories of challenging behaviour were shown by children with Down's syndrome.[670] A number of studies have examined the persistence of specific forms of challenging behaviour among cohorts of people with learning disabilities.

- *Self-injury:* Reported persistence rates for self-injury have varied from 54 per cent over a three-year period[673 674] to 90 per cent over a 10-year period, with the majority of studies reporting persistence rates of approximately 75 per cent.[675 676 677]
- *Aggression:* In a two-year follow-up of 118 adults with intellectual disabilities, extremely high levels of persistence of aggression were reported.[678]

  Other studies have found a similar pattern of persistence of aggressive behaviour.[679 680]

While there is ample evidence that behavioural interventions may bring about significant reductions in challenging behaviour over the short to medium term, evidence from long-term follow up studies indicates that such gains rarely involve the elimination of challenging behaviour and may be difficult to sustain. *All* of the 52 individuals who had received treatment in a specialised facility for people with severe self-injurious behaviour still required 'high-level behaviour management programmes' eight years later, for example.[681 682] Single case studies show a similar pattern.

Very few studies have attempted to identify personal or environmental characteristics associated with variations in the persistence of challenging behaviours. One study[685] reported that persistence of 'more demanding' challenging behaviour among 179 people between 1988 and 1995 was associated with participants in 1988 showing: more severe challenging behaviour; more severe self-injurious behaviour (and specific topographies of self-injury); more frequent stereotypy; more severe intellectual disability; poorer communication skills, self-care skills and less ability to use money; lower ability to occupy themselves constructively or to behave appropriately in social situations.

Another found[686] that self-injury status at follow-up was predicted by three variables: site of injury (higher persistence being shown by people exhibiting head directed self-injury); reported (greater) stability of self-injury when first identified; and (younger) age. A further study examined the personal and environmental characteristics associated with people being re-referred to a crisis intervention service.[687] It was reported that, among younger participants, not living with their family and exhibiting self-injurious behaviour were the strongest predictors of re-referral. Among older participants, aggression was the strongest predictor of re-referral.

As a result, even where an intervention has proved very successful – perhaps changing radically the environment in which a person lives and how the challenging behaviour is responded to – it will still be vulnerable to changes over time. A member of staff leaving, for example, may not only reduce the available skills in the staff team, but may also cause a grief reaction in the person with learning

disabilities. In such a situation it is very easy to revert to old, familiar and effective challenging behaviours.

For these reasons, it is essential to monitor psychological interventions for people with learning disabilities and challenging behaviour over the long term.

13.6 Evaluating generalisation

If an intervention is carried out in one setting or over a restricted time period, then attempts should be made to assess whether there has been any impact in other settings or at other times.

Level of evidence to support this guideline: 3
Good practice

If the challenging behaviour is presenting as a problem in other settings or at other times, then a specific programme to ensure generalisation may need to be set up.
There is evidence from the applied behavioural literature that generalisation is a persistent area of difficulty. This may be because of the specialist setting in which many of the interventions were researched. Interventions in the community where people live or work seem to have fewer problems.[688]

There is some evidence to suggest that people with milder learning disabilities can generalise through self-monitoring and self-management.[689] But many people with learning disabilities appear to have a difficulty with this skill.[690] Further research on how people with learning disabilities can learn, should help to develop this area of clinical work.

Evaluating whether there has been any generalisation is the first step towards a new set of work in the new setting.

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14. Detailed guidelines – Feedback

14.1 Feedback

Definition: Feedback in this context is the communication of information about the process and the effectiveness of an intervention for challenging behaviour.

Many services have guidelines on the timeliness and content of psychological reports and letters, which need to be adhered to as one essential element of good practice.

The term 'feedback' should be understood more broadly to include verbal and informal communication – both person-to-person and over the telephone, e-mail or fax.

14.2 Providing Feedback

Feedback should be provided at several stages:

1. **at the end of the assessment period, when the psychological formulation has been arrived at;**
2. **after interventions, whether these are successful or not;**
3. **when there is a substantial revision to the psychological intervention or the proposed intervention plan;**
4. **on completion of work with an individual.**

This is a minimum standard: it is good practice to provide feedback on a more regular and frequent basis.

Level of evidence to support this guideline: 3
Good practice

This guideline is based on clinical consensus. There was a strong feeling at the conference that good communication about the work with challenging behaviour was a very important part of the process, and that when it was neglected, poor relationships could develop and the effectiveness of the psychologist's work was greatly undermined.

Most services have guidelines for when letters or reports should be sent. This guideline may therefore need to be adapted to fit into local standards and expectations. It does present a minimum standard and we would suggest that a significantly lower local guideline might not meet the requirement to keep colleagues, carers and people with learning disabilities adequately informed.
Perhaps because it is seen as basic good practice, there seem to be no studies which look at the effectiveness of providing different amounts of feedback (or none at all).

14.3 Recipients of feedback

Feedback should be given to the person with learning disabilities in a form that can be understood and is respectful.

People who are involved in the assessment or intervention should receive regular and routine feedback.

The referrer and other important people in the life of the person with learning disabilities should also receive regular and appropriate feedback.

Level of evidence to support this guideline: 3
Good practice

The guideline on 'meeting the person who is challenging' (Guideline 10.6) provides advice on communicating with people with learning disabilities.

There is some evidence for the effectiveness of presenting feedback in different modalities or formats. Visual presentations, for example, are very important for people with autism.[691] [692] The use of video feedback to help a person understand their own behaviour can be very helpful.

The most important factor in providing feedback for staff and families appears to be 'goodness of fit' with the environment, recognising the skills, preferences and styles of the people being communicated with. For example, the use of visual representations (graphs, bar charts, pie charts or scatter plots) can be very helpful for some people, while others find numbers or narrative easier.

14.4 Confidentiality of feedback

Psychologists must ensure that they respect the confidentiality of the person with learning disabilities when they are giving feedback.

Level of evidence to support this guideline: 3
Essential practice

This guideline is agreed by clinicians to be essential practice. Confidentiality is an essential component of the British Psychological Society Code of Conduct and any other statement of ethical practice by health practitioners.

It is particularly important for psychologists working with people who are not socially valued and often not seen as active agents in their own lives to be mindful of the requirement to respect confidentiality. There is anecdotal evidence to suggest that breaches of confidentiality are more likely to occur with more disabled and more disadvantaged groups of people.

Sometimes clinicians are perplexed about whether family members or paid carers should be provided with personal information about the person with learning disabilities. The following factors should be considered:

- The person with a learning disability should be asked, when possible, what information they do or do not wish to share with other specified people. The tendency for people with learning disabilities to be acquiescent to requests of this sort should be allowed for in assessing someone's consent to sharing information.
- There is no obligation to pass on information unless there is a serious risk to a person or others for whom they have some responsibility. A parent, for example, does not have a right to know everything about their adult son or daughter.
- Where there is a serious risk to the person with a learning disability or others, the psychologist does have an obligation to tell those who need to know so that they can take steps to protect others or themselves.
- The relationship with a close family member is often of central importance in the life of a person with learning disabilities. The psychologist needs to consider this when making a decision to share or to withhold information. It may be necessary to work alongside the family to strengthen relationships so that they can offer mutual trust, safety and the capacity for development.
- It may be helpful to consider what information would be shared in similar circumstances if the person did not have a learning disability.

14.5 Eliciting feedback

As well as providing feedback to others, the psychologist should also make serious attempts to elicit feedback from other people on his or her own performance.

Level of evidence to support this guideline: 3
Essential practice

Feedback must be conceptualised as a two-way process. Psychologists should welcome feedback from other people about their work with individuals, family carers and staff teams that support people who present challenges, and use it to improve their practice.

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15. Conclusions

The aim of these guidelines is to act as a stimulus to improve clinical practice. The process of producing the guidelines has helped improve the practice of the authors (we believe), but we hope they will be of wider usefulness.

We have tried to make the guidelines clear, unambiguous, measurable and achievable.

They must be clear and unambiguous if they are to be useful in clinical practice.

We hope that they are measurable enough to act as the basis for an audit tool. The audit cycle is one way of looking at what we do and trying find ways of improving it.

One of the most active debates during the development of the guidelines has been how to set a standard in the guidelines, which is high but still achievable. We are aware that trying to assess what we actually do against what we think we should be doing can be a negative and demotivating experience. But we do believe very strongly that when we are working with people with severe and enduring difficulties, it is important to motivate ourselves and maintain our commitment by setting goals and standards that we should be aiming to achieve. As with our clinical experiences of setting goals for clients, it is of course essential to monitor our success in achieving the goals after we have set them.

During the consultation period for these guidelines, concerns were raised that defining effective clinical practice might lead to less innovation and creativity in responding to challenging behaviour. We would be very reluctant to see this happen, as using our psychological skills creatively is a great source of satisfaction in our daily work, and we believe this to be true of many of our colleagues.

However, we also recognise the drive to be 'hero innovators'[693] can lead us into continually 'reinventing the wheel' and searching after new panaceas, rather than learning from previous experiences. As there is a relatively good evidence base for interventions for challenging behaviours, we believe this should be our starting point. From this point it is important to expand and develop our knowledge by evaluating and disseminating new ideas and new practices, as well as expanding and refining the old ones.

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- publishes books in partnership with Blackwells;
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Division of Clinical Psychology

Faculty for People with Intellectual Disabilities

Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood

A document compiled by a Working Group of the British Psychological Society's Division of Clinical Psychology, Faculty for People with Intellectual Disabilities

Membership of the Working Group

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Executive Summary

This document has been produced as guidance for clinical psychologists who are frequently asked to assess whether or not an individual has an intellectual disability. It will also be of use to commissioners, colleagues in intellectual disability services and families and individuals who are seeking clarification on this issue. The aim is to outline good practice in this area. It also considers the different contexts in which assessment of intellectual disability may be relevant, including mental health and mental capacity legislation, court proceedings, service entitlement and the family courts.

Intellectual disability is defined as significant impairment in intellectual functioning and significant impairment in adaptive behaviour (social functioning), with each of these impairments beginning prior to adulthood. In practice, a diagnosis of intellectual disability is sometimes made without reference to all three criteria and with debate over the meaning of scores on an assessment of intellectual functioning (usually known as an IQ test). This has resulted in confusion for families, service users and care providers and consequent difficulties in ensuring that individuals receive an appropriate service.

This document seeks to clarify the components of an assessment, considers the meaning of the 'scores' that are obtained and outlines the means by which psychologists reach their opinion in relation to whether or not an individual has an intellectual disability. It provides guidance on technical issues, and notes the difficulties associated with assessing intellectual functioning for people who have an intellectual disability. It also notes the relevance of psychologists using their clinical judgement in interpreting complex information.

The document recommends specific measures that should be used, and provides guidance on how findings should be presented. It also notes the importance of ensuring that assessment is undertaken by an appropriately qualified psychologist. A further recommendation is that a judgement as to whether or not an individual has an intellectual disability should only be made when all three components of the assessment are carried out by an appropriately qualified professional, who is able to justify their opinion in accordance with this guidance. This would reduce confusion for individuals, families and services.

Introduction

This document has been produced by the Faculty for People with Intellectual Disabilities of the Division of Clinical Psychology, the British Psychological Society (the Society), to provide updated guidance to psychologists registered with the Health and Care Professions Council (HCPC) who may be required to assess the presence of intellectual disability, or the extent of intellectual disability, in adults. Intellectual disability is the term used internationally to describe what was previously known as learning disability. The term intellectual disability will be used throughout this document.[1]

National and international definitions of intellectual disability generally share three key criteria. These are:

- a significant impairment of intellectual functioning;
- a significant impairment of adaptive behaviour (social functioning); with
- both impairments arising before adulthood.

These criteria are embodied in mental health and mental capacity legislation in the United Kingdom. They are also evident in the major diagnostic classification systems of the American Association on Intellectual and Developmental Disabilities *(AAIDD)*, the American Psychiatric Association *(Diagnostic and Statistical Manual of Mental Disorders, DSM)* and the World Health Organisation *(International Classification of Diseases, ICD)*. All three of these major diagnostic frameworks have either been recently revised *(DSM-5, AAIDD-11)* or are in the process of being revised *(ICD-11)*. An increased emphasis has been placed in these revisions on the importance and appropriate assessment of adaptive behaviour, but the basic criteria incorporating limitations in intellectual and social functioning, with difficulties arising before adulthood, remain.

Recent years have seen increased pressure on services in relation to determining who is eligible to access them, and there are a number of legal frameworks where an intellectual disability can be a significant consideration in terms of actions, responses and rights. Accurate assessment is, therefore, becoming increasingly important.

Concern has been expressed about the impact of 'labelling' on the lives of people with learning disabilities. The Society acknowledges that a label, or diagnosis, can have a negative impact on how people with intellectual disabilities are perceived and the way they are treated. However, providing an assessment of a person's needs, and placing this in the context of their need for services, is more likely to be of benefit than a general assessment which does not signpost the way to focused support. One purpose of assessment and diagnosis is to assist in the development and provision of appropriate support and interventions aimed at benefitting the person's functioning and quality-of-life.

Concern has also been expressed about the use of 'IQ tests' as part of the process of determining whether or not a person has an intellectual disability. (These are tests of general intellectual functioning, so called due to their results typically being expressed in terms of an 'intelligence quotient', or IQ.) There has been considerable scientific debate on the accuracy of IQ testing for people with an intellectual disability, and there have been

[1] A number of different terms have been used over time to describe intellectual disability. See Appendix 1 for more detail.

claims that the IQ score is of little relevance in this context. The Society's view is that the use of an IQ assessment is an essential component of the overall assessment of intellectual disability.

This is partially to ensure that United Kingdom definitions are in line with international organisations and classification systems (e.g. *DSM-5*, *ICD-10/11, AAIDD-11*), and also to assist in recognising and responding to the specific difficulties experienced by persons who have an intellectual disability. A significant (or severe) intellectual impairment, which arises in childhood, will have an impact on a person's social and intellectual functioning. Services that are supporting those with an intellectual disability need to recognise this in order to focus on their specific needs, which are likely to be different in certain respects from those experienced by individuals with other impairments. It is largely for this reason that the definition of intellectual disability, nationally and internationally, consists of criteria which require properly quantified impairments in intellectual and social functioning, and that these impairments began before adulthood.

The Society is also aware that carrying out a detailed assessment requires a skilled clinician and can take time. Services that are under pressure may sometimes seek to 'shortcut' this, either by using some form of screening tool or by carrying out only part of an overall assessment (which can lead to an overreliance on the IQ score, for example). The Society strongly recommends that this should not be accepted as good practice.

On the other hand, the Society recognises that some form of initial screening may be appropriate, so that a more detailed assessment is reserved only for those who definitely need it. For example, it is unlikely that an individual who has passed several GCSEs at grade C or above will have an intellectual disability. However, persons conducting screening assessments should not carry out shortened versions of either intelligence and/or adaptive behaviour assessment measures and then rely upon the results of these alone to determine whether or not an individual has an intellectual disability.

The Society recommends that IQ assessments are carried out either directly or under the supervision of appropriately qualified psychologists who are skilled in the assessment of adults who may have an intellectual disability and who are registered with the HCPC. Psychologists who undertake IQ tests should meet the criteria required by the publishers and distributors of the tests they use. The same should apply to the assessment of adaptive behaviour, since tests of adaptive behaviour are increasingly norm referenced and psychometrically based as well. In addition, the Society recommends that appropriate consent is sought in respect of any person being assessed.

The Society recognises that the decision as to whether or not an adult has an intellectual disability (or determining the extent of an individual's intellectual disability) is complex. It is not merely a matter of adding up numbers from various assessments, deciding whether or not any impairments started when the person was a child and then making a determination on that basis. As with any diagnosis, the clinician needs to make a judgement about the information gathered and how it contributes to the overall opinion. For this reason, *clinical judgement* (see below, Section 4.1) is recognised as an important component of any assessment. It is essential that any clinicians carrying out such assessments are transparent about what they have done and are able to justify their opinions.

This document is divided into five sections. Section 1 considers the various contexts in which an assessment of the presence, or extent, of an intellectual disability might be necessary. Section 2 examines the definition of intellectual disability, as well as its three essential criteria. Section 3 looks at a number of issues in relation to the assessment of intellectual disability, including the tools that should be used, how to conduct an assessment and the kinds of factors that may impact upon the results of an assessment. Section 4 considers how to interpret the findings of an assessment, with particular reference to the place of clinical judgement in that process. Section 5 considers how to report the results of an assessment of intellectual disability.

Although this document is written primarily for psychologists, the Society hopes it will also be of use to others – including other health and social care professionals, families and those involved in the legal system.

Section 1: Contexts

Psychologists are frequently asked to assess if an individual has an intellectual disability in the context of determining whether or not they have access to a number of legal and civil rights. These rights may be to the provision of either community care or health services. Psychologists may also be asked to assess in the context of an individual being either an alleged victim or perpetrator of a crime, of the applicability of mental health legislation, or of proceedings in the Family Court or the Court of Protection.

In deciding whether it is appropriate to undertake an assessment, psychologists need to be able to justify clearly the reason why the assessment is necessary. It needs to have a purpose; the process can be stressful and difficult for the person being assessed and it should not be undertaken without an adequate reason.

1.1 England and Wales

Community care

Community care legislation (e.g. the National Health Service and Community Care Act 1990, the Care Act 2014) requires local authorities to carry out an assessment of needs for services. To be eligible for this assessment, a person must appear to the local authority to be someone who has needs for care and support. Adults with intellectual disabilities are one of the groups to whom this definition applies. Decisions as to whether or not they have eligible needs should be made after the assessment.

Determination of whether or not an individual has an intellectual disability can often be the first part of this process. There can be an overreliance on the use of IQ scores in the process, as it can seem like a simple and clear-cut measure. It is, therefore, essential that psychologists give clear explanations of their rationale for stating whether or not an individual meets the criteria for an intellectual disability, that all three parts of the definition are explored and addressed, and that issues around 'cut-off' scores are clarified in the context of the overall clinical picture.

Psychologists should also consider whether refusal to carry out a full assessment in the circumstances could result in the individual being denied access to services to which they have a right and which they may need.

People with autistic spectrum disorder may not meet the criteria for an intellectual disability. This should not necessarily exclude them from access to a community care assessment, however, as they may still be considered 'disabled' within the meaning of community care legislation. This is because the definition of 'disabled' includes people 'with a mental disorder of any kind'. For example, s1(2) of the Mental Health Act 1983 defines mental disorder as 'mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of mind', so it is possible for individuals with autistic spectrum disorder to be considered eligible for community care services under that particular definition.

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Access to benefits

The benefits system is complex, but people with intellectual disabilities are entitled to certain benefits on the basis of their disability. Psychologists may be asked to assess whether or not a person has an intellectual disability in order to assist in a benefits claim. Many services refuse to do this, unless it is also in the context of eligibility for services.

Mental Health Act 1983 and Mental Health Act 2007

The Mental Health Act 2007 amended s1(2) of the Mental Health Act 1983 and states that a 'person with intellectual disability shall not be considered by reason of that disability to be:

(a) suffering from mental disorder for the purposes of the provisions mentioned in subsection (2B) below; or

(b) requiring treatment in hospital from mental disorder for the purposes of sections … unless that disability is associated with abnormally aggressive or seriously irresponsible conduct on his part'.

This means that an intellectual disability (defined as 'a state of arrested or incomplete development of the mind which includes significant impairment of intelligence and social functioning') does not, on its own, constitute sufficient grounds for treatment under this Act.

Psychologists may be asked to assess whether or not an individual has an intellectual disability in the context of being treated for a mental illness. If this occurs whilst they are in hospital being treated for a mental illness, then carrying out an assessment under these circumstances should be approached with extreme caution, as the validity of any results obtained is likely to be called into question.

Mental Capacity Act 2005

The Mental Capacity Act 2005 provides the legal framework to allow for the making of decisions on behalf of adults who lack the capacity to make a decision (or decisions) for themselves. It seeks to provide a balance between autonomy of decision-making and protection for those who are vulnerable and lack capacity. It therefore allows for 'unwise decisions' for those who have capacity to make such decisions. For those who lack capacity, decisions should be made in their 'best interests'. (The courts have noted that it is unlikely that an unwise decision would be in an individual's best interests if they lack capacity.)

The Act provides a definition of incapacity in two parts. The first part defines a person who lacks capacity as follows: 'a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain' (s2(1)).
The associated Code of Practice states that '[e]xamples of an impairment or disturbance in the functioning of the mind or brain may include the following:

- conditions associated with some forms of mental illness;
- dementia;
- significant learning disabilities [intellectual disabilities];
- the long-term effects of brain damage;
- physical or medical conditions that cause confusion, drowsiness or loss of consciousness;
- delirium;
- concussion following a head injury; and
- the symptoms of alcohol or drug use' (4.12).

An intellectual disability may, therefore, be one, but it is never the only, aspect of whether or not individuals are able to make decisions for themselves. To lack the capacity to make a specific decision, they also need to fulfil the second part of the two-stage test, which requires that they are 'unable: (a) to understand the information relevant to the decision; (b) to retain that information; (c) to use or weigh that information as part of the process of making the decision; or (d) to communicate [the] decision (whether by talking, using sign language or any other means)' (s3(1)).

Psychologists may be asked to assess decision-making capacity in a number of areas, including medical treatment, where to live, contact with friends and family, etc. It may be important as part of a determination to assess whether or not the person has an intellectual disability. However, it should not always be essential to carry out a full assessment of whether or not the person has an intellectual disability, as this information may be readily available in his/her records.

It is important to note that a number of decisions are excluded under the Mental Capacity Act 2005, including capacity to consent to sexual relationships, to marry, to divorce and to consent to adoption (s27(1)).

Deprivation of Liberty Safeguards

Deprivation of Liberty Safeguards form part of the Mental Capacity Act 2005. They apply only to individuals who lack capacity. Psychologists may be asked to assess whether or not an individual has an intellectual disability as part of this process. If the request is made while the person is acutely ill and in hospital, it is appropriate for the psychologist to comment on the reliability and validity of the results obtained, and perhaps suggest that an assessment should wait until the person has recovered (by which time it may no longer be necessary, of course). If the person is already resident in a care home, it is likely that a determination as to whether or not he/she has an intellectual disability will already have been made.

Parenting assessment

Referrals for assessment of intellectual disability in these circumstances should be considered very carefully, and psychologists are referred to the Society's *Good Practice Guidance for Clinical Psychologists when Assessing Parents with Learning Disabilities* (2011). One of the issues that this document considers is the relevance of IQ as a predictor of parenting ability in adults with intellectual disabilities. It should be noted that 'emergency' parenting assessments are likely to be invalid (and possibly unethical).

Sexual relationships and marriage

Although these issues are specifically excluded from the Mental Capacity Act 2005, the principles of the Act are used in the determination of a person's capacity to make decisions in these respects. Intellectual disability is not sufficient grounds to presume that an individual cannot engage in a sexual relationship or to marry. However, there is significant case law on the criteria to be used when considering these decisions, and psychologists are encouraged to keep up to date with case law relating to this (and to other decisions requiring an assessment of mental capacity).

Fitness to plead

A person who is 'under a disability' and who may have committed an offence may not be considered fit to plead within the criminal justice system. Determination of whether or not they are 'under a disability' can impact upon decisions to prosecute, whether the person can participate in the court process and sentencing/disposal decisions. The Mental Health Act 2007 defines mental disorder as 'any disorder or disability of the mind' and intellectual disability is considered to be a clinically recognised mental disorder. Psychologists may, therefore, be part of the process of assessment to determine whether or not an individual has an intellectual disability.

Vulnerable witnesses

People with intellectual disabilities are deemed to be vulnerable witnesses within the meaning of the Youth Justice and Criminal Evidence Act 1999. The definition of a vulnerable witness within that act includes any witness who '(i) suffers from mental disorder within the meaning of the Mental Health Act 1983, or (ii) otherwise has a significant impairment of intelligence and social functioning' (s16(2)).

Vulnerable witnesses are entitled to the provision of 'special measures' if they are required to appear in court as a witness. Psychologists may be asked to assess whether or not they have an intellectual disability; however, any decision as to the provision of special measures is a matter for the judge to decide.

Immigration/Deportation

Psychologists may be asked to assess whether or not a person has an intellectual disability in the context of applications to remain in the United Kingdom. It is often the case that someone appealing against an immigration decision in these circumstances either does not have English as their first language or speaks no English at all. Assessment of intellectual functioning, adaptive behaviour and developmental history in these circumstances is extremely problematic, and findings may not be valid.

1.2 Scotland

National drivers and strategy

The Scottish Government has published two strategy documents relating to individuals with learning disabilities in the past 14 years: *The Same as You?* (2000) and *The Keys to Life* (2013). The latter recognises that there are many different definitions of intellectual disability, and argues that those which include problems in adaptive behaviour are likely to be the most appropriate when planning statutory services and supports. Both documents describe individuals with intellectual disabilities as having a significant, lifelong condition that started before adulthood, that affected their development and which means they need help to: (i) understand information; (ii) learn skills; and (iii) cope independently. This definition is also used by the Mental Welfare Commission for Scotland, which has statutory duties to ensure that care, treatment and support are lawful and that they respect the rights and promote the welfare of individuals with mental illness, intellectual disability and related conditions.

Often psychologists in Scotland are asked to assess whether or not an individual has an intellectual disability in order to determine access to services.

Legislation

There are three key pieces of legislation relating to intellectual disability in Scotland: the Mental Health (Care and Treatment) (Scotland) Act 2003, which sets out powers and duties in relation to people with mental disorder; the Adults with Incapacity (Scotland) Act 2000, which provides means to protect and make decisions about financial affairs and welfare for persons with incapacity; and the Adult Support and Protection (Scotland) Act 2007, which makes provision for the protection of vulnerable adults from any harm including but not restricted to physical, psychological and financial harm. Psychologists are increasingly involved in adult support and protection proceedings, working alongside local authority and police colleagues.

The key definition in Scotland for legal purposes is that of 'mental disorder', as found in s328 of the Mental Health (Care and Treatment) (Scotland) Act 2003. It includes 'learning disability … however caused or manifested'. The requirement for this definition to be met in relation to the various provisions contained within the above acts is usually determined through medical evidence. However, circumstances may arise where others are required to provide information to support a diagnosis, for example, at a mental health tribunal or a court where the diagnosis of intellectual disability is borderline or contested. Psychologists are frequently asked to contribute to the assessment of capacity, particularly in situations where the medical practitioner primarily responsible views the assessment of capacity as complex.

1.3 Northern Ireland

In Northern Ireland, clinical psychologists in particular play a pivotal role in determining intellectual disability, and very often act as gatekeepers to what have for many years been combined (health and social services) Adult Intellectual Disability Services.

The Mental Health (Northern Ireland) Order 1986 remains operative in Northern Ireland, although it is currently under review. This recognises three distinct categories of intellectual disability: 'mental handicap'; 'severe mental handicap'; and 'severe mental impairment'. 'Mental handicap' is defined as 'a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning'. 'Severe mental handicap' is defined in exactly the same way, save that the impairments of intelligence and social functioning are 'severe' rather than 'significant'. And 'severe mental impairment' is defined in exactly the same way as 'severe mental handicap', save that there is an additional requirement that it 'is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned'. 'Severe mental impairment' is, therefore, defined exactly as in the Mental Health Act 1983. However, unlike the 1983 Act, the Mental Health (Northern Ireland) Order 1986 has no category of 'mental impairment'. Apart from mental illness, the only ground for guardianship it recognises is 'severe mental handicap', and the only ground for detention in hospital for treatment is 'severe mental impairment'. In both cases, therefore, *severe* impairments of both intelligence and social functioning have to be demonstrated – and psychologists are often asked to conduct assessments with a view to determining whether individuals display such levels of impairment.

There is currently no provision within Northern Ireland for explicit capacity legislation, other than case law. However, it is anticipated that the legislation that will replace the current Mental Health (Northern Ireland) Order 1986 will apply, within a single legislative framework, not just to matters of mental health, but to wider health and social care provision and to financial matters as well. The test for capacity is likely to be broadly the same as applies in the Mental Capacity Act 2005, so it is anticipated that psychologists will play a significant role within the new legislation once it comes into effect.

Section 2: Defining intellectual disability

Many of the contexts identified above involve their own, specific definitions of intellectual disability (or related terminology), and psychologists should adhere to these when carrying out assessments to determine whether or not the requirements of those definitions are fulfilled. Generally, and where no specific definition is involved, the Society recommends that a diagnosis of intellectual disability requires the demonstration of three essential criteria:

- significant impairment of intellectual functioning;
- significant impairment of adaptive behaviour; and
- onset before adulthood.

These three criteria are perhaps most readily identifiable in the most recent definition proposed by the American Association on Intellectual and Developmental Disabilities *(AAIDD-11)*:

> *Intellectual disability is characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disability originates before age 18.*

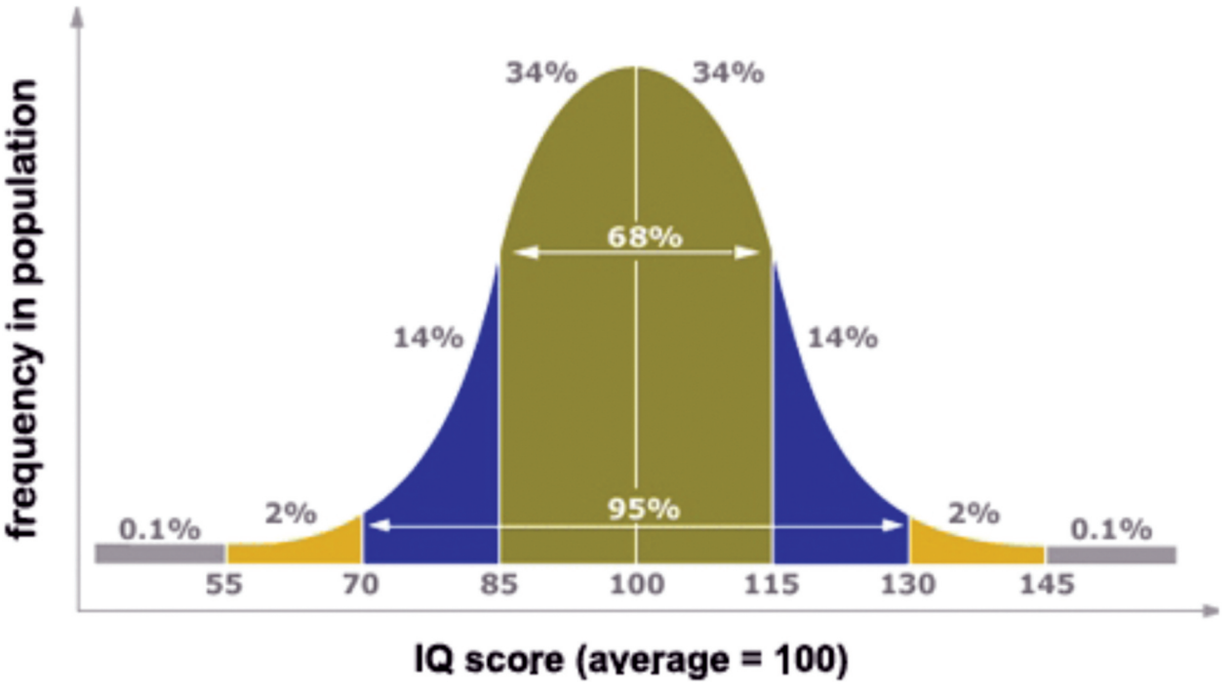
This section considers each of the three essential criteria for intellectual disability in more detail. The first refers to intellectual functioning, the second to adaptive behaviour (social functioning) and the third to age of onset.

2.1 Significant impairment of intellectual functioning

Considerable debate and disagreement continues regarding the definition of intelligence. *AAIDD-11* defines it as 'a general mental ability [which] includes reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly and learning from experience'. This reflects the general consensus of research findings presently, which support a hierarchical model of intelligence (Whitaker, 2013). It assumes a general factor of intelligence that can be summarised as a single figure (generally, the 'intelligence quotient', or IQ) which in turn is comprised of a number of semi-independent factors that are highly correlated with IQ and, to a lesser extent, with each other.

IQ scores are determined by reference to a normal distribution within the population, generally with a mean of 100 and a standard deviation (SD) of 15. The majority – just over two-thirds – of the general population may be expected to fall within one SD either side of the mean (that is, within the IQ range 85 to 115). As scores deviate further from the mean, in either direction, the numbers in the population with corresponding levels of IQ become progressively smaller. This is demonstrated by the normal distribution curve. However, there is in practice a 'bump' at the lower end of the IQ distribution, resulting in a relative over-representation of individuals with IQs below about 50 to 55 in particular. This is attributable to a much higher frequency of organic and/or genetic factors amongst those at the lower end of the distribution, and represents an additional 0.5 per cent (approximately) of the population with IQs at the very lowest levels.

For several decades now, it has been accepted generally that a 'significant impairment of intellectual functioning' is best represented by an IQ score derived from an appropriately standardised and norm-referenced assessment measure that is more than two SDs below



the population mean, allowing for the expected level of measurement error within the test (see below, Section 4.1). On tests with a mean of 100 and a SD of 15, this equates to an IQ of less than 70 approximately. This is the criterion recommended by all three major international classification systems currently (*DSM-5*, *ICD-10* and *AAIDD-11*). It is also the criterion recommended by the British Psychological Society. Based upon the normal distribution curve, and allowing for the previously mentioned 'bump' at the lower end of that curve, this means that just over 2.5 per cent of the general population may be expected to have a level of intelligence commensurate with a diagnosis of intellectual disability.

In the United Kingdom it is almost exclusively the role of applied psychologists to undertake the individualised psychometric assessments which produce the IQ scores considered valid for the purpose of establishing a diagnosis of intellectual disability. This has been a longstanding role for psychologists, who receive specific training in the administration, scoring and interpretation of intelligence tests.

2.2 Significant impairment of adaptive behaviour

Appreciation of the term adaptive behaviour has evolved over the years and, based upon a number of factor analytic studies dating back to the 1960s (Tassé et al., 2012), there is currently a broad consensus as to what it involves. Thus *AAIDD-11* defines 'adaptive behaviour' as 'the collection of conceptual, social and practical skills that have been learned and are performed by people in their everyday lives', while *DSM-5* says that 'adaptive functioning' concerns 'activities of daily life' and 'involves adaptive reasoning in three domains: conceptual, social and practical'.

These two major classification systems each include a number of skills as examples of the three major domains of functioning, and although these lists are not identical, there is considerable overlap between them. Thus, for example, *AAIDD-11* presents the following as examples of skills comprising each of the three domains:

- *Conceptual skills:* language; reading and writing; and money, time and number concepts;
- *Social skills:* interpersonal skills, social responsibility, self-esteem, gullibility, naivety (i.e. wariness), follows rules/obeys laws, avoids being victimised, and social problem-solving;
- *Practical skills:* activities of daily living (personal care), occupational skills, use of money, safety, health care, travel/transportation, schedules/routines, and use of the telephone.

Only relatively recently have measures been developed for the assessment of adaptive behaviour (certainly, as defined in terms of these three key domains of functioning) that are norm-based and that have been standardised on a representative sample of the general population. It is, therefore, possible now to assess and report upon adaptive behaviour in much the same way as it has for many years been possible to do for intellectual functioning. That being the case, and in line with *AAIDD-11* in particular, the Society recommends that a 'significant impairment of adaptive behaviour' is best represented by a score derived from an appropriately standardised and norm-referenced assessment measure that encompasses either: (i) any one; or (ii) all three of the domains of conceptual, practical and social skills that is more than two SDs below the population mean, allowing for the expected level of measurement error within the test concerned (see below, Section 4.1). On tests with a mean of 100 and a SD of 15, this equates to a score of less than 70 approximately.

Given that measures for the assessment of adaptive behaviour are increasingly norm referenced and psychometrically based, the Society recommends that assessments of adaptive behaviour, just as those of intellectual functioning, should be carried out by appropriately qualified psychologists who are skilled in the assessment of adults who may have an intellectual disability. Psychologists who undertake assessments of adaptive behaviour should meet the criteria required by the publishers and distributors of the tests, and be registered with the HCPC.

2.3 Age of onset prior to adulthood

DSM-5 defines the last of its three essential criteria for intellectual disability as follows: 'Onset of intellectual and adaptive deficits during the developmental period'. *AAIDD-11* is more explicit: 'This disability originates before age 18'.

Accordingly, the Society recommends that, for the criterion 'onset before adulthood' to be met, there should be evidence of the presence of each of the other two criteria in the period before the person attains (or attained) the age of 18 years.

2.4 Levels of intellectual disability

Until relatively recently, it was common to identify, specifically on the basis of IQ, four discrete levels of intellectual disability – mild, moderate, severe and profound. *ICD-10* still adheres to this practice, although it is anticipated that the forthcoming *ICD-11* will not. Certainly, sub-classification on the basis of IQ alone was abandoned in favour of an individual's intensity of support needs in *AAIDD-9* (1992), while *DSM-5* proposes a system of sub-classification (again, mild, moderate, severe and profound) that is based upon adaptive functioning rather than IQ.

The Society endorses the view that there is generally little to be gained from sub-classifying persons with intellectual disability on the basis of IQ alone. However, it recognises that there may be occasions when it is appropriate to distinguish between levels of intellectual disability – such as when seeking to highlight an individual's level of support-needs, for example, or when there is a legal requirement for such distinction to be made (as arises with specific aspects of the Mental Health (Northern Ireland) Order 1986, for example – see above, Section 1.3). Specifically, the Society accepts that it may at times be appropriate for psychologists and other clinicians to distinguish between 'intellectual disability' and 'severe intellectual disability'.

Whereas intellectual disability is defined as comprising 'significant' impairments of both intelligence and adaptive behaviour (both impairments evident before adulthood), the criteria for severe intellectual disability are as follows:

- severe impairment of intellectual functioning;
- severe impairment of adaptive behaviour; and
- onset before adulthood.

Operationally, the Society recommends that, whereas 'significant' impairments are best represented by scores derived from appropriately standardised and norm-referenced assessment measures of intelligence and adaptive behaviour that fall more than two SDs below the population mean (allowing for the expected level of measurement error within the tests concerned), 'severe' impairments are those that fall more than three SDs below the mean on such measures. On measures with a mean of 100 and a SD of 15, this latter equates to scores of less than 55 approximately.

Section 3: Assessing Intellectual Disability

3.1 Gathering preliminary information

An individual's account of his/her history and any past or current difficulties, alongside his/her behaviour in the course of an assessment interview, can provide important information regarding the presence, nature and impact of any cognitive difficulties that he/she may have (Spreen & Strauss, 1998). Therefore, taking a detailed background history may be invaluable in assessing whether or not a person has an intellectual disability. Not only may crucial historical details be secured during an interview, but information can be gained about the individual's general appearance, eye contact, use of vocabulary, social interaction, and so on. However, it is usually beneficial to have this information supplemented, where possible, by information from other sources too.

Such an interview does not necessarily follow a fixed format, albeit it is generally useful for it to cover the following:

- Family and social history;
- Developmental history (birth, pregnancy, developmental milestones);
- Health problems as a child;
- Input from other professionals, both as a child and as an adult;
- Educational history (types of schools, statements of special educational needs);
- Occupational history (both paid and voluntary);
- Medical history (physical and psychological difficulties, head injury, epilepsy);
- Mental health issues;
- History of emotional care and support (including known attachment difficulties);
- Significant bereavements;
- Family interpretations of the person's difficulties;
- Previous cognitive assessments (seeing the original reports, if possible);
- Current medication;
- Vision and hearing;
- Language;
- Motor difficulties;
- Cultural issues.

Several of these can have a direct bearing upon, and can therefore assist in determining whether, the last of the three criteria for intellectual disability in particular has been met.

3.2 Selecting appropriate assessment measures

Measures for the assessment of intellectual functioning

Ideally, only the most recent versions of measures of intellectual functioning that fulfil all four of the following criteria should be used in an assessment of intellectual disability:

- they should be designed for individual (not group) administration;
- they should have been constructed on the basis of the normal distribution of general intelligence, and standardised using a representative sample of adults from across the United Kingdom;
- they should possess psychometric properties (reliability and validity) that lie within the range of scientific acceptability; and

- they should be based upon a multidimensional, hierarchical model of intelligence, producing not just an overall score but also related index or composite scores.

There exists currently just one assessment measure that fulfils all four of these criteria: the *Wechsler Adult Intelligence Scale – Fourth UK Edition (WAIS-IV UK)* (Wechsler, 2010). This is the latest version of what has for many years been the most widely used measure of assessment of adult intelligence in the United Kingdom. Accordingly, the Society recommends that the *WAIS-IV UK* should be the test of choice in assessments of a person's level of intellectual functioning. In addition to a Full-scale IQ (FSIQ), it produces four index scores – Verbal Comprehension (VCI), Perceptual Reasoning (PRI), Working Memory (WMI) and Processing Speed (PSI) – all from 10 core subtests. (A further five, optional subtests are available for substitution or more detailed assessment.) The *WAIS-IV UK* has been normed for use with persons aged 16 to 90 and, uniquely amongst similar measures, it was standardised on a sample of 270 United Kingdom adults. Test-retest reliability for the American sample has been reported at 0.96. However, there is evidence to suggest that *WAIS-IV UK* test results may be less accurate in the lower ranges of ability (Whitaker, 2012).

It may not always be either appropriate or possible to use the *WAIS-IV UK* with a particular individual, in which case the psychologist involved may wish to consider an alternative means of assessing the person's level of intellectual functioning. Especially in cases where time is limited or when the person is known to have limited powers of concentration, the *Wechsler Abbreviated Scale of Intelligence, Second Edition (WASI-II)* (Wechsler, 2011) may be considered. However, this employs just a small number of subtests (four, or even just two) so, despite its reporting both Verbal and Performance IQs in addition to a FSIQ, it is doubtful if the *WASI-II* could be said to fulfil the criterion of a multidimensional, hierarchical model of intelligence. Nevertheless, the *WASI-II* can certainly be useful on occasions, particularly in circumstances where it is not possible to administer a *WAIS-IV* and/or for screening purposes. (Its scores may be transferred and incorporated directly into a subsequently-completed *WAIS-IV*, from which those subtests already completed as part of the *WASI-II* can therefore be omitted.) In cases where the individual being assessed does not have an adequate use of English, the *Leiter International Performance Scale, Third Edition (Leiter-3)* (Roid, Miller et al., 2013) may be considered as an alternative to the *WAIS-IV UK*. This is the latest version of a completely non-verbal test of intelligence, which is claimed to be culture-free. However, it has not been standardised in the United Kingdom and concerns have been expressed about the accuracy and reliability of earlier versions of the scale, particularly in the lower ranges of ability (Glenn & Cunningham, 2005).

Whatever the assessment measures employed, the psychologist concerned should at all times be mindful of their specific limitations and should take care to administer them and interpret their results accordingly. Also, as already indicated, psychologists should ensure that they always use only the most recent versions of any tests they employ.

Measures for the assessment of adaptive behaviour

Avery and Sullivan (2013) highlight that the assessment of adaptive or social behaviour is less clearly defined than that of assessing intellectual functioning, and that there is no clear agreement on how adaptive behaviour should be assessed or on which is the best assessment measure to use for that purpose. Typically, measures of adaptive behaviour comprise a series of items reflecting a number of specific skill domains. Most recently, these domains have been defined as comprising conceptual, social and practical skills.

Respondents are asked to indicate whether, and to what extent, the person being assessed performs each of a series of behaviours in the course of their daily lives. Although the individual being assessed may also serve as the respondent, it is generally advisable that some other person – but who nevertheless knows the individual well – be approached to provide the necessary information. The results are typically presented as a score for each domain separately and for the scale as a whole.

Ideally, any measures of adaptive behaviour that are employed as part of an assessment of intellectual disability should comply with each of the following:

- they should have been constructed on the basis of an essentially normal distribution of adaptive behaviour, and standardised using a representative sample of adults from across the United Kingdom;
- they should possess psychometric properties that lie within the range of scientific acceptability;
- they should be based upon a multidimensional, hierarchical model of adaptive behaviour, producing not just an overall score but also composite scores in respect of each of the conceptual, social and practical domains;
- they should be appropriate for the age, gender, socio-cultural background, religion and community setting of the person who is being assessed; and
- they should be completed by someone who knows the person being assessed very well – and only exceptionally by that individual him/herself.

A number of measures for the assessment of adaptive behaviour are currently available, but unfortunately none of them complies fully with all of the above. Two come closest: the *Adaptive Behaviour Assessment System, Second Edition (ABAS-II)* (Harrison & Oakland, 2003) and the *Vineland Adaptive Behaviour Scales, Second Edition (Vineland-II)* (Sparrow, Cicchetti & Balla, 2005). Each of these is available in multiple forms, according to the relationship between the respondent and the person being assessed, and each has adequate psychometric properties. They both are based on scales where the mean is 100 and the SD is 15 – so they both allow for a ready determination of whether any given score falls more or less than two SDs below the mean. However, both have been standardised using representative samples of the American general population only. A major difference between the two measures is in the organisation of the skills they assess. The *Vineland-II* comprises three main sections (Communication, Daily Living, and Socialisation), whereas the *ABAS-II* addresses 10 adaptive-skill areas across the three domains of Conceptual, Social, and Practical skills. The *ABAS-II* is likely to be the more directly relevant to the current definition of intellectual disability, therefore. Nevertheless, the *Vineland-II* has certain advantages as well – not least its ability to present an individual's raw scores as 'age-equivalents' (albeit age-equivalents must always be interpreted with caution). Psychologists should bear in mind both the strengths and weaknesses of the two measures, as well as the purposes for which they are to be used, when deciding upon which to adopt in any particular situation.

Other measures for the assessment of adaptive behaviour are also available. These tend not to be based upon a normal distribution, however, nor have they been constructed with the key domains of Conceptual, Social, and Practical skills directly in mind. For a recent review of measures of adaptive functioning, see Tassé et al. (2012).

As with measures for the assessment of intellectual functioning, psychologists conducting assessments of adaptive behaviour should at all times be mindful of the specific limitations of any tests they use, and they should take care to administer such tests and interpret their results accordingly. Also, psychologists should ensure that they always use only the most recent versions of any tests they employ.

3.3 Conducting an assessment

A number of factors need to be borne in mind when conducting assessments of either intellectual functioning and/or adaptive behaviour. These are discussed below, in turn.

Factors in the assessment of intellectual functioning[2]

The Setting/Environment

There is very little research on the effect of the environment on cognitive ability. However, it is known that unfavourable conditions not only affect well-being but also mental performance (Klatte, Wegner & Hellbrück, 2005). The *WAIS-IV* manual highlights that testing should take place in a well lit, quiet room that is free from distraction. It also describes suitable seating and how to set up the test materials.

Mental health

The relationship between specific psychiatric diagnoses and performance on tests of intellectual abilities is neither straightforward nor well understood: people with the same diagnosis may be affected in different ways, and the same individuals may be affected in different ways at different times. Self-evidently, assessments should not be conducted with individuals who are distressed or who are not oriented to place and time. As a general rule, however, testing conducted either during or immediately after a period of detention under mental health legislation should be avoided if at all possible, since the results obtained are unlikely to be either valid or reliable. Likewise, assessments should generally not be carried out either just before or just after a woman gives birth (as may be requested in relation to child care proceedings, for example): the results of such assessments too could be questioned in terms of their validity.

Medication

There is growing evidence that many pharmacological agents – whether prescription, over-the-counter or illegal – can influence neuropsychological functioning (Hartman, 1995). It is unclear to what extent such medications may influence the performance of any one individual at a particular time. However, it is generally accepted that any medication will have its greatest effect upon an individual's performance during the first few weeks of its prescription and for two weeks after its withdrawal. This should be taken into account when an assessment is being planned.

Fatigue

Fatigue can be caused by relatively long-term factors such as chronic mental or physical health problems, disabilities and associated medications, as well as by more immediate and fluctuating factors such as recent sleep disruption, poor nutrition or acute illness.
It reduces test performance, so assessments should not be undertaken when it is suspected that a person is unduly fatigued. Psychologists should enquire – preferably from a third

[2] This section discusses a number of personal and environmental factors that may impact upon the administration of a test of general intellectual functioning with a given individual. A list of other, higher-level factors that may impact upon the assessment of intelligence are discussed in *AAIDD-11* (pages 35–41).

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party in addition to the person being assessed – about the individual's level of fatigue. In addition, psychologists should remain alert throughout the assessment to other indicators of fatigue, such as a marked drop in performance or restlessness, and be prepared to pause or postpone the assessment as necessary.

Motivation

For test results to be considered valid, it is important that the individual being assessed gives of his/her best throughout the assessment process. Each of the factors already identified can affect motivation. So too can the context of a person's referral for assessment, including who has requested the assessment and for what purpose. It is, therefore, important that the psychologist addresses carefully the issue of consent throughout the process. Specifically, if an individual objects to an assessment, even though it may be in his/her best interests for that assessment to proceed, this could significantly affect the results obtained. Clearly, a valid assessment cannot be completed against an individual's will or where any form of coercion is involved.

Effort

In some circumstances, an individual may deliberately under-perform during a formal assessment (e.g. in an attempt to gain access to benefits, services or activities, or to avoid the criminal justice system). Where this is suspected, the psychologist should consider and, where indicated, formally assess the person's effort throughout the assessment. This should be done in line with guidance in the Society's 2009 publication, *Assessment of Effort in Clinical Testing of Cognitive Functioning for Adults.*

Language, culture and ethnicity

It is becoming increasingly common for psychologists to be asked to assess persons who do not have English as their first language. The validity of such assessments can be problematic, for a variety of reasons: rapport can be hard to establish and there can be difficulties in relaying specific test instructions – neither of which will necessarily be ameliorated by the use of interpreters and/or non-verbal assessment materials;[3] persons educated abroad may have had limited educational opportunities and/or experience of formal assessments and may be suspicious of same; and many tests have been shown to be culturally biased and/or have been normed and standardised with reference to just a single country's population, such that persons from other cultures or populations may be disadvantaged when presented with them. All of these increase the likelihood of someone being diagnosed with an intellectual disability who does *not*, in reality, fulfil the criteria for that label. Psychologists should, therefore, consider each of the following when carrying out assessments of persons from different cultural backgrounds:

- Recognise and acknowledge any cultural differences;
- Seek to offer a culturally sensitive environment;
- Conduct an initial, comprehensive clinical interview, in an attempt to understand any relevant cultural nuances and differences;

[3] The *WAIS-IV UK* manual covers some of the issues that need to be considered when using interpreters and when assessing across communication modalities, including the use of sign language, simultaneous communication, cued speech and aural/oral communication.

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- Be aware of the potential difficulties in using interpreters (e.g. an interpreter may misunderstand and/or misinterpret instructions, providing either too little or too much information to either the examiner or the person being assessed, and this could invalidate the results);
- Highlight the above difficulties, particularly in respect of how they have impacted upon the interpretation of any test results obtained, in clinical reports.

Sensory and other impairments

The *WAIS-IV* manual warns against attributing poor performance on cognitive tests to low intellectual ability when in fact some form of physical, language and/or sensory difficulties may be responsible. Clinicians need to be aware that there may need to be adaptations made when assessing individuals with these additional difficulties. The *WAIS-IV* manual recommends that when testing individuals with additional needs a battery of measures should be used, and that any adaptations from standardised administration procedures should be documented. Clinical judgement (see below, Section 4.1) should be applied to evaluate the effects of any such modifications on the scores obtained. However, the verbal subtests of the *WAIS-IV* can be administered equally to persons with and without a visual impairment. Also, the *WAIS-IV* manual lists a number of issues that should be considered when testing individuals who are deaf or have hearing impairments.

Factors in the assessment of adaptive behaviour

The aim of an assessment of adaptive behaviour is to indicate the extent to which a person can function independently. Ideally, estimates of adaptive behaviour should be provided by third-party informants who know the person well and are familiar with his/her functioning in daily living. However, measures of adaptive behaviour are open to the personal biases of informants (who may either wittingly or unwittingly underestimate the person's abilities in an attempt to obtain services, for example, or overestimate them through a reluctance to acknowledge the person's limitations) and psychologists should employ clinical judgement to interpret the scores that are derived accordingly. One safeguard against such bias is to secure assessments of the person's adaptive behaviour from informants across more than one setting (e.g. home and work). In addition, it may be helpful to undertake some direct observation and/or assessment of the individual. Conceptual skills such as reading, spelling and numerical skills, for example, may be assessed directly through specific tests of these skills.

Section 4: Interpreting the results of an assessment

This section concerns the interpretation of data collected throughout an assessment, particularly in relation to whether the individual concerned fulfils the criteria for a diagnosis of intellectual disability, but also in relation to other clinically significant insights that the data might provide.[4]

In relation to a diagnosis of intellectual disability, the key concern is whether the person has significant impairments of both intellectual functioning and adaptive behaviour, acquired before adulthood. Essentially, 'significant' here means more than two SDs below the population mean; 'intellectual functioning' refers to a Full-scale IQ score; 'adaptive behaviour' refers to a score on a standard measure of Conceptual, Social, Practical or General adaptive behaviour skills; and 'before adulthood' means prior to the age of 18 years.

The overall determination, based on all three criteria, will be one of the following:

- that the person fulfils the criteria for intellectual disability;
- that the person does not fulfil the criteria for intellectual disability; or
- that it has not been possible to determine whether or not the persons fulfils the criteria for intellectual disability.

The assessment should also consider the profile of scores produced by the individual, and the significance of any discrepancies there may be between those scores.

4.1 Clinical judgement

Interpreting the results of assessments of intellectual functioning and adaptive behaviour requires the psychologist to exercise 'clinical judgement'. This is defined by *AAIDD-11* as 'a special type of judgement rooted in a higher level of clinical expertise and experience. It emerges directly from extensive data and is based on training, experiences, and specific knowledge of the person and his or her environment' (p.85). Essentially, it is the application by the psychologist of his/her knowledge of the tests, the scores and what they mean, their knowledge and expertise in relation to intellectual disability, and their clinical observation of the person whom they are assessing currently, to arrive at a conclusion that is transparent in its reasoning and justifiable both to the person being assessed (where possible) and to external parties.

Crucially, the psychologist needs to consider the extent to which the derived scores are likely to reflect the person's 'true' abilities. A number of factors must be considered, including the fact that test scores always carry a margin of error. This is usually presented in normative tables as a 90 per cent or 95 per cent confidence interval (i.e. the range of scores within which there is a 90 per cent or 95 per cent probability that the person's true score is located). These confidence intervals, which are generally reported in test manuals, are derived from a statistical model that assumes a normal distribution of scores within the population. However, for most tests they are based primarily upon data from a sample of the general population that under-represents the 'bump' at the lower end of the distribution curve (see above, Section 2.1). This means that the margin of error for a

[4] Clinicians should also be aware that there may be a need to support individuals when a diagnosis of intellectual disabilities is made. They will need to explain what it means and recognise that the individual may need assistance in both understanding what the diagnosis means and how to adjust to it.

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person's true score at that extreme of the distribution is likely to be greater than the published confidence intervals suggest. Some empirical evidence supports this inference in relation to the Wechsler tests in particular (e.g. Whitaker, 2013).

As part of the exercise of clinical judgement, it is important for the psychologist to interpret any information gathered about the person's history alongside any factors from that history that may have influenced the person's performance on the tests attempted subsequently, such as deprivation, a chaotic upbringing or later life, abuse, etc. (see above, Section 3.1). These factors do not necessarily negate the possibility of an intellectual disability, but they may contribute to the person's functioning in an impaired manner. It is also important to record and take account of relevant factors concerning the tests employed and the ways in which those tests are believed to measure intellectual functioning and adaptive behaviour respectively (Section 3.2). Finally, it is important to interpret and take account of qualitative observations of the person's engagement with and approach to the tests presented (Section 3.3), for example, Did they work hard? Were they persistent? Did they use trial-and-error or other strategies? Did they talk themselves through the test? Did they appear anxious? Did they comment on how they were doing?

4.2. Significant impairment of intellectual functioning

On standard tests of intellectual functioning, this amounts to whether the person's 'true' IQ is likely to fall above or below the cut-off of two SDs below the population mean. In other words, is the person's true IQ likely to be at least 70, or is it more likely to be 69 or below? There are four possibilities here:

- If the derived score is well below 70, such that even the top of the selected confidence interval for the score is no higher than 69, then, providing there are no compelling reasons from the person's history or performance on the test to suggest otherwise, it may be concluded that the criterion for a 'significant impairment of intellectual functioning' has been met.
- If the derived score is well above 70, such that the bottom of the selected confidence interval for the score is no lower than 70, then, providing again there are no compelling reasons from the person's history or performance on the test to suggest otherwise, it may be concluded that the criterion for a 'significant impairment of intellectual functioning' has not been met.
- In all other eventualities, including where the derived score falls very close to 70, such that the selected confidence interval includes both 69 *and* 70, the psychologist must exercise clinical judgement to determine the person's true IQ, and from that to establish whether or not the criterion for a 'significant impairment of intellectual functioning' has been met.
- Exceptionally, even with the exercise of clinical judgement, it may not be possible for the psychologist to reach a determination as to whether or not the criterion of a 'significant impairment of intellectual functioning' has been met.

Broadly speaking, whereas there are many factors that may decrease performance and so lead to an under-estimate of IQ, there are very few that can increase performance and thereby lead to an over-estimate of IQ. As indicated above (Section 3.3), factors that can decrease performance include an inappropriate (e.g. noisy) testing environment, stress or anxiety, depression or other mental health problems, attention problems, medication,

fatigue, low self-esteem or self-confidence, visual, auditory or other physical disabilities, and reduced effort. In contrast, the only major factors associated with over-estimates of IQ are 'teaching to the test' (coaching) for verbal subtests and too short a test-retest interval for performance (non-verbal) subtests.

If any of the factors known to influence performance on tests of intellectual functioning are suspected (Section 3), further assessment may be prompted and the matter should be discussed in the subsequent report of that assessment (Section 5). Evidence of such influence may be present in the profile of subtest scores. For example, the influence of depression is greater on subtests requiring rapid performance (e.g. digit symbol substitution), while that of attention-deficit is greatest on tests requiring sustained attention (e.g. digit span). If a specific relationship is identified (for example, an individual who has been identified as depressed does show a specific weakness on timed tests), then the derived IQ score should be recomputed omitting the anomalous subtest(s). The purpose of such a re-calculation is to give the psychologist an indication of the extent to which the original IQ estimate may be biased: it feeds into the psychologist's clinical judgement, although it should never substitute for the original estimate, which should always be reported.

As well as considering a person's Full-scale IQ, it is good practice to interpret the derived index scores, any discrepancies between them, and any strengths or weaknesses in individual subtests. A good report should provide not only a 'verdict' on whether or not a person fulfils the criteria for a 'significant impairment of intellectual functioning', but also an analysis of the full test profile.

4.3 Significant impairment of adaptive behaviour

Unlike intellectual functioning, adaptive behaviour is generally assessed indirectly by psychologists, using third-party reports. This requires that the psychologist is able to identify an informant who knows the individual sufficiently well to provide reliable data. It follows that an assessment should not be conducted in the absence of a reliable informant, in which case a direct (observational) assessment of the individual's adaptive behaviour may be required instead.

Generally, though, as with intellectual functioning, a 'significant impairment of adaptive behaviour' is best understood as a level of performance on a standard measure that is more than two SDs below the general population mean. On measures where the mean is 100 and the SD 15, this equates to a score of less than 70. Unlike with intellectual functioning, however, where this applies to just a single, overall score (the Full-scale IQ), such a level of performance in respect of any one of four possible areas – Conceptual, Social, Practical or General (overall) adaptive skills – is sufficient for the criterion of a 'significant impairment of adaptive behaviour' to be met. This means that any differences that are found within an individual's profile of adaptive behaviour abilities, whilst undoubtedly informative, will have only a limited impact on the decision as to whether or not the criterion for a 'significant impairment of adaptive behaviour' has been met.

Again, it is the individual's 'true' level of performance that is the crucial factor and, also again, there are four possibilities within the realm of adaptive behaviour:

- If the derived score in *any one* of the four domains of Conceptual, Social, Practical or General adaptive skills is well below 70 (regardless of performance in the other three), such that even the top of the selected confidence interval for that score is no higher

than 69, then, providing there are no compelling reasons to suggest that the person's true level of performance is other than this, it may be concluded that the criterion for a 'significant impairment of adaptive behaviour' has been met.

- If the derived score in *all four* of the above areas is is well above 70, such that the bottom of the selected confidence interval for all four scores is no lower than 70, then, providing there are no compelling reasons to suggest that the person's true level of performance is other than this, it may be concluded that the criterion for a 'significant impairment of adaptive behaviour' has *not* been met.
- In all other eventualities, including where any (or all) of the derived score(s) are very close to 70, such that the selected confidence interval includes both 69 and 70, the psychologist must exercise clinical judgement to determine the person's true level of adaptive behaviour, and from that to establish whether or not the criterion for a 'significant impairment of adaptive behaviour' has been met.
- Exceptionally, even with the exercise of clinical judgement, it may not be possible for the psychologist to reach a determination as to whether or not the criterion of a 'significant impairment of adaptive behaviour' has been met.

Using clinical judgement, the psychologist should seek to establish if any impaired functioning on the part of the individual being assessed is due to an intellectual disability or if it could be due instead to some other cause, such as a physical or sensory disability, mental illness, ADHD, or substance abuse, for example. If an alternative account of the impairment is suspected, this should trigger further assessment (e.g. a mental health screening), which in turn may lead to the individual being signposted towards services other than specialist Intellectual Disability Services. If further assessment identifies factors additional to intellectual disability that are potentially remediable (e.g. mental health problems), then this raises the possibility that whilst the individual fulfils the criterion for impairment of adaptive behaviour at this time, his/her adaptive functioning might improve in the future to the point where the criterion would not be met. This prospect clearly will depend upon the extent of the current impairment, and clinical judgement should be used when deciding on how this matter should be reported.

4.4 Age of onset prior to adulthood

This criterion is understood operationally as an age-of-onset prior to the individual's eighteenth birthday. This means that there should be evidence of the presence of each of the other two criteria before the person attains the age of 18 years. Such evidence will often be available from those individual(s) providing information on the person's adaptive behaviour and/or background details, with other possible sources including historical educational, developmental and medical records, for example.

After considering the available evidence, the psychologist should determine whether this third criterion for an intellectual disability has or has not been met. Only very exceptionally should it prove impossible to come to one of these determinations. For example, in cases where no direct evidence of the age-of-onset criterion can be found (such as may occur when an individual's first encounter with Services is as an adult), then, if an assessment identifies the presence of impairments both of intellectual functioning and adaptive behaviour it will usually be reasonable to conclude that those impairments are long-standing and, therefore, that the criterion has been met. Exceptions to this

include situations where there is evidence of events that could have compromised brain functioning (for example, a road traffic accident, a stroke or serious mental illness) having occurred only after the age of 18 years.

4.5 Severe intellectual disability

The criteria for severe intellectual disability are identical to those for intellectual disability, save that the impairments of intellectual functioning and adaptive behaviour must be 'severe' rather than 'significant'. This means that the cut-off for scores on standard measures of both intellectual functioning and adaptive behaviour for the criteria of a 'severe impairment of intellectual functioning' and a 'severe impairment of adaptive behaviour' respectively are set at 55 rather than 70. In all other respects, the processes for deciding upon whether an individual fulfils the criteria for severe intellectual disability are exactly as detailed above, in Sections 4.2 to 4.4, for intellectual disability.

4.6 The need for concurrence of the three criteria

Intellectual functioning and adaptive behaviour are not highly correlated: in adults, the correlation may be as low as 0.2 (Sparrow et al., 2005), although somewhat higher correlations, of around 0.5, have been reported in children (Whitaker, 2013). This is reflected in the fact that of the just over 2.5 per cent (approximately) of the population whose IQs are believed to be under 70, just a quarter to a third are known to Intellectual Disability Services; this implies that many people with this level of cognitive ability are nevertheless able to function adequately in their everyday lives and so do not fulfil the criterion of a 'significant impairment of adaptive behaviour'. Conversely, there are many people whose adaptive behaviour is impaired but whose IQs are above 70, who are known to services as 'vulnerable adults', and who fulfil the criteria for certain other conditions, such as autistic spectrum disorder, personality disorder, etc. (It is generally true that people who are referred to services have deficits in their adaptive behaviour; indeed this usually is the reason why they need help and are referred in the first place.)

For a diagnosis of intellectual disability (or severe intellectual disability) to be made, all three of the essential criteria, separately, must be fulfiled. This means that someone with a *significant* (or even *severe*) impairment in one of the two domains of functioning only (i.e. intellectual functioning and adaptive behaviour), and with no significant impairment in the other, may not be adjudged to have an intellectual disability. Similarly, for *severe* intellectual disability, severe impairments of *both* intellectual functioning and adaptive behaviour must be evident.

It is ideally essential, therefore, that when seeking to determine whether or not a person has an intellectual disability, assessments should be carried out both of intellectual functioning *and* of adaptive behaviour. However, it is recognised that this may not always be possible (for example, when a physical disability prevents an IQ assessment or when no appropriate informant can be found to provide the information necessary for an assessment of adaptive functioning). In cases where it is possible to undertake only one half of the recommended assessment (i.e. of intellectual functioning or adaptive behaviour), the psychologist must employ clinical judgement to reach an overall determination, and this should be made clear in any subsequent report. Note that this form of assessment is not recommended, however, and should be undertaken only in exceptional circumstances.

Section 5: Reporting on assessments

It is likely that most reports prepared by psychologists within the area of intellectual disability address the issue of whether or not a person may be said to have an intellectual disability – that is, whether or not he/she fulfils the three essential criteria of significant impairments of both intellectual functioning and adaptive behaviour, both of which become evident before the age of 18 years. It may be that this is the only reason for an assessment – to determine a person's eligibility for Intellectual Disability Services, for example. Often, however, there may be other reasons as well – such as determining a person's 'capacity' in relation to a particular matter (Section 1). Both the amount and nature of the information that is derived will vary accordingly, and that in turn will impact upon the format and content of any report that is prepared subsequently.

Most of the guidance provided in this section concerns the reporting of assessments undertaken to determine the presence or absence of intellectual disability. However, reference will be made where appropriate to assessments carried out for other purposes too. Whilst recognising that the content and presentation of any report may be influenced by local circumstances and is ultimately at the discretion of the psychologist involved, the Society recommends that reports on assessments within the area of intellectual disability should consider the following areas (cf., Lichtenberger & Kaufman, 2013):

- Identifying information;
- Reason for referral;
- Background information;
- Appearance and behavioural observations;
- Tests administered;
- Test results and interpretation;
- Summary, diagnostic impression and recommendations.

5.1 Identifying information

The report should present information identifying the person being assessed, including his/her name, age, gender, date of birth and address. It is essential that these details are reported clearly and accurately. If the person is known by more than one name, then all names used should be reported.

5.2 Reason for referral

The report should state both the source of the referral and the reason(s) for it. Also, the issues to be addressed within the report – which will not necessarily be the same as those highlighted in the referral (in which case the reasons for any discrepancies should be given) – should be summarised. For example, if the assessment set out to determine whether or not a person has an intellectual disability (or, in certain circumstances, a severe intellectual disability), the three essential criteria should be summarised: (i) a significant (or severe) impairment of intellectual functioning; (ii) a significant (or severe) impairment of adaptive behaviour; and (iii) onset before adulthood.

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5.3 Background information

The report should summarise any relevant information in relation to the individual prior to the current assessment. This may include developmental, medical (including other diagnoses), sensory, educational and vocational information, as well as current living and support arrangements and the results of any previous assessments. Such information may not be available in every case, of course.

Issues of consent should also be addressed in the report – in particular, whether the subject of the assessment had provided consent before the referral and/or at the time of the initial appointment or, in the event of his/her not being able to provide valid consent, the basis on which the assessment has proceeded in his/her best interests.

Finally, the date and venue of any appointment(s) arranged both with the person being assessed and/or with anyone acting as informant on his/her behalf should be specified.

5.4 Appearance and behavioural observations

The person's presentation both initially and throughout the assessment should be described, with particular emphasis on any factors that might have impacted upon his/her performance on the tests attempted.

5.5 Tests administered

Since all three criteria for intellectual disability must be met before a determination can be made, it is necessary for any assessment report to consider the evidence in relation to each of the three criteria, first separately and then collectively. Details should be provided of the name and version of all standardised assessment measures used, and a brief description should be provided of each of those measures.

5.6 Test results and interpretation

The report should provide details of all relevant information derived throughout the assessment process. For each of the three criteria separately, the following should be presented:

- a description of the criterion to be met;
- a summary of the measure(s) used in relation to that criterion;
- the results obtained; and
- a determination as to whether or not the criterion has been met.

It is a matter for individual psychologists to decide on the level of detail with which to present test results. However, the Society is mindful of a tendency amongst non-psychologists to misinterpret the results of psychometric assessment measures presented in the form of single, standardised scores (such as IQs). The Society, therefore, strongly recommends that neither individual IQ scores nor their equivalents in respect of adaptive behaviour measures should be cited in psychological assessment reports. If test scores are deemed to be necessary, they should be reported not as single figures but as *ranges* of scores (e.g. 'within the range 67 to 77'), in accordance with the statistical properties of the specific tests that have been used and with details provided of the probability (generally either 90 per cent or 95 per cent) that the person's 'true' scores fall within the specified ranges.

The psychologist's decision as to whether or not each criterion has been met should be specified, along with an outline of the process that was followed in reaching each determination. This will generally be as detailed above, in Sections 4.2 to 4.4 (and, in the case of severe intellectual disability, Section 4.5). Specifically, the psychologist's opinion as to the person's *true* levels of both intellectual functioning and adaptive behaviour should be presented and discussed. This will involve detailing not just the actual ranges of scores derived throughout the assessment, but also the extent to which the psychologist, using his/her clinical judgement, believes that those scores were impacted by any personal factors that may have come to light throughout the assessment (e.g. the person's mental health and general attitude towards the assessment) or the list of other factors that are known to be possible influences on psychometric test performance identified above (in Section 3). Only exceptionally is it likely that the psychologist's estimate of a true level of functioning will fall outside the reported range of scores. However, the psychologist should always report the reasons for his/her determination in this regard in any event.

Likewise, the psychologist should present his/her decision with regard to an overall diagnosis of intellectual disability: provided *all three criteria* have been met this should be confirmed, otherwise it should not (Section 4.6). However, if either of the two 'impairment' criteria has proven impossible to be determined currently, then, provided none of the criteria has been adjudged to fall outside the intellectual disability range, any formal decision as to whether or not the individual has an intellectual disability should be deferred, pending either the production/availability of additional information or a re-assessment at a later date (generally in at least a further 12 months' time). In the meantime, an interim determination may be made – either that the person has or does not have an intellectual disability – and this may allow for the temporary provision of specialist Intellectual Disability Services, for example. Equally, psychologists should not be reluctant to highlight transient factors that may have depressed a person's scores on one or both assessments, such that he/she may at some time in the future no longer meet the criteria for a diagnosis of intellectual disability.

Once the matter of a possible diagnosis has been dealt with, the report should detail and discuss any significant discrepancies between the person's performances on different subtests of the measures completed.

5.7 Summary, diagnostic impression and recommendations

If the individual is adjudged to have an intellectual disability, the report should focus on the person's specific strengths and weaknesses, with a view to identifying and, where appropriate, making recommendations on both the nature and level of any support needs that are (likely to be) required.

Similarly, if the individual's status with regard to intellectual disability is currently unclear and a decision deferred, the report should identify any specific strengths and weaknesses and indicate both the nature and level of any support needs that are (likely to be) required over the next few months.

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If the individual is adjudged not to have an intellectual disability, then whilst there should be no *requirement* for a psychologist (within Intellectual Disability Services) to present a detailed analysis of the person's strengths and weaknesses – other than insofar as they might relate to any other service (e.g. Mental Health Services) to which the psychologist believes the person should be referred – to do so will usually be appropriate.

In any case, an indication should be provided of the response of the person who has just been assessed (and/or, if appropriate, of that person's carers) when informed of the outcome of the assessment and of the recommendations being made.

Finally, an indication should be given of whether a user-friendly version of the current report, specifically for the person who has been assessed, is to be prepared.

Appendix 1: Intellectual disability and comparable terminology over the years

The last century has seen a number of terms introduced to refer to the condition that forms the subject of this guidance manual. Within the United Kingdom, these have ranged from 'mental deficiency' to 'mental subnormality', 'mental handicap' and, most recently, 'learning disability', whereas in other jurisdictions – most notably the United States – the term 'mental deficiency' gave way first to 'mental retardation' and then, currently, to 'intellectual disability'.

Each revision has sought to reflect the current understanding of the condition, while at the same time cancelling the often pejorative associations that have tended to develop over time with whatever terminology has been adopted.

In the United Kingdom, the term 'learning disability' was first used officially in 1991. Whilst it has certainly been more socially acceptable than the term which immediately preceded it – 'mental handicap' – 'learning disability' has unfortunately been prone to confusion with another term, 'learning difficulty', which had been introduced a short time previously within the educational sector. (The phrase 'learning difficulty' was first adopted in the Education Act 1981, to refer to *any* condition or disability, for example, a profound hearing impairment or dyslexia, which results in a child having a 'greater difficulty in learning than the majority of children of the same age [and] which prevents or hinders the child from making use of ordinary educational facilities'. This means that a child who has a 'learning disability' will by definition also have a 'learning difficulty' – but that only a proportion of children who have a 'learning difficulty' may be said to have a 'learning disability'.) The two terms are ***not*** synonymous. Although they are often used – incorrectly – as though they are referring to the same condition, they are in fact quite distinct.

There is a growing consensus, both nationally (especially in academic circles) and internationally (cf., the latest edition of the 'definition manual' of the American Association on Intellectual and Developmental Disabilities – previously the American Association on Mental Retardation) that the term 'intellectual disability' should be adopted now as the preferred term.[5] Consequently, the term 'intellectual disability' has been used throughout this guidance.

[5] *Intellectual Disability: Definition, Classification, and Systems of Supports*, 11th Edition (Washington: AAIDD, 2010).

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Appendix 2: The consultation process

We developed this guidance in response to requests from Faculty members, in recognition that there have been a number of changes in services and legislation since the publication of the Society's previous guidance in 2000 *(Learning Disabilities: Definitions and Contexts)*.

We carried out a consultation process, which consisted of workshops, consultation of Faculty members and consideration of reported experiences of the responses of service users to the assessment process. The draft document was sent to a number of people, including some Faculty members who work on clinical training schemes (that is, as well as people who work only in clinical services). We went through a number of drafts on the basis of feedback received.

We held two conferences/workshops in England and Scotland, involving a total of approximately 150 people. The main issues that were raised were: (a) whether we should be using any labels at all for people with intellectual disability; and (b) whether we should use IQ tests as part of the assessment process. There was a range of views on this issue, and the majority view (by a large majority at the workshops) was that diagnosis was required in a large number of situations (including access to services and greater understanding of an individual's strengths and problems), and that formal assessment methods (including IQ testing) were the most reliable and effective method of doing this. This approach is also in accordance with international definitions and approaches to assessment.

We recognised the issues about error at the lower end of scores and, therefore, we have emphasised in this guidance the importance of assessing all three components of the definition of intellectual disability, the use of robust assessment methods and the significance of clinical judgement.

The consultation process also considered how to write reports, and this guidance is included in the document.

Our aim is to provide practical guidance on both assessment and report writing. We think there is a need for psychologists to be transparent about how they come to a conclusion that someone has an intellectual disability, and that they are able to justify their opinions.

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Notes

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The British Psychological Society

Incorporating Attachment Theory into Practice: Clinical Practice Guideline for Clinical Psychologists working with People who have Intellectual Disabilities

June 2017

June 2017

Membership of the Working Group
This document has been prepared by the Faculty for People with Intellectual Disabilities of the Division of Clinical Psychology.

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Foreword

The work of John Bowlby and attachment theory has informed my thinking in various ways throughout my career. Therefore, I am delighted to have been invited to write this foreword to the guidelines. At the start of my psychology career in the 1970s, A-level texts presented Bowlby's attachment theory beside the famous study by Harry Harlow, in which a Terry cloth-covered wire monkey was preferred by infant monkeys to a bare wire 'mother' with a feeding tube. At that time, Bowlby's work, summarised in the World Health Organisation (WHO) publication *Infant Care and Mental Health* (1951) was subject to strong feminist critique, characterised as reinforcing traditional gender roles for women. As a new father myself, I lamented the baby books and guides of the time, which were clearly aimed at mothers, not fathers. Thus, Bowlby's initial interpretation that early maternal deprivation could cause irreversible and long-term psychological damage may have been influenced by the times in which he was writing. His initial findings were largely based on 44 children in a relatively deprived orphanage (Bowlby, 1946), but his research was very carefully carried out and showed a definite association between lack of affection and delinquency – thankfully, it turns out that such damage is not as irreversible as Bowlby originally thought.

The umbrella construct of *primary maternal deprivation* caused a debate that unfortunately overshadowed Bowlby's ground-breaking development of attachment theory. By the time I had undertaken my PhD in child development, Rutter's (1981) revision of maternal deprivation in *Maternal Deprivation Reassessed* had concluded that discord and disharmony of family breakdown predicted poor mental health, rather than primary maternal deprivation. However, the developing and interacting bonds that people experience in their lives offer continuing risks and continual opportunities for improved psychological health, and attachments continually reflect current mental wellbeing.

But what about fathers? In my first book with Jaqueline McGuire entitled *Fathers; Psychological Perspectives,* we were rather upbeat about the changing role of fathers (Beail & McGuire, 1982). Disappointingly, my research at that time did not find much change in parenting roles (Beail, 1985). However, it would be fair to say that much has changed since then, and it is now accepted that children develop multiple attachments, which are developed into a hierarchy of strengths.

Thankfully, attachment theory became more prominent in the 1980s in the clinical understanding of psychological development. As a trainee clinical psychologist, I was taught by two psychoanalysts, Brian Lake and Dorothy Heard, who knew and, in the case of Dorothy, worked with Bowlby; Brian supervised some of my clinical work. At that time, Dorothy and Brian were working on the concept of the attachment dynamic in adult life (Heard & Lake 1986). Work such as this demonstrates that attachment theory is not just about child development, but about development across the lifespan.

Also at this time, I carried out an observational study of profoundly multiply disabled children living in a hospital for 'mentally handicapped people'. My observations found that the children spent over 80 per cent of their time not interacting with anyone (Beail, 1985). This was in sharp contrast to children with similar disabilities living with their parents

where the time spent in interaction was the complete reverse (Beail, 1988). Although my project had a behavioural focus, I was left wondering about the internal worlds and emotional development of these children.

When I qualified as a clinical psychologist in 1984, I began working in a joint post in child development and intellectual disabilities (ID). My placement had been in a large hospital for people who have ID, but service philosophies were changing from hospital to community care, and new posts appeared in community teams (see Beail, 2016). The client group was also different as the community team served the community rather than only those placed in hospital. Those in hospital were also being repatriated to their communities. I had come to the view that people who have ID were being offered a very limited range of interventions, often by indirect behavioural methods. I started to work psychodynamically with some of my clients. I came into contact with Pat Frankish and Valerie Sinason who were also offering this approach to people who have ID. It was not surprising that working with adults with developmental delays needed to be informed by the work of child psychotherapists and theorists. As well as the ideas of Klein and Winnicott, Bowlby's ideas were also playing a central role in the developing model of disability psychotherapy (Frankish, 2016).

In the mid-1980s, attachment theory became more prominent in our thinking in ID services due to the work of Jennifer Clegg (e.g. Clegg & Sheard, 2002) and then Carlo Schuengel and his colleagues (e.g. Schuengel et al., 2013). Over time, these ideas have been increasingly incorporated into clinical practice with people who have ID, and hence the need now for some clinical guidelines.

These guidelines focus on incorporating attachment theory into clinical practice. For those who are not familiar with attachment theory, the guidance provides a summary before it examines research in attachment with people who have ID. There are service user and carer accounts of the attachment issues in their own life journeys, and then clinical guidance on incorporating attachment theory into our practice. The guidance invites us to think about direct clinical work with individuals, but also more systemic applications.

I would like to congratulate the working group of the faculty for people who have intellectual disabilities for their dedication and commitment to this project. They have produced excellent clinical practice guidelines, which I hope will inform and develop the practice of clinical psychologists and others who serve people who have ID.

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Executive Summary

The aim of this guideline is to inform clinical psychologists and others about attachment theory and how it can be applied to the health and social care of people with intellectual disabilities (ID). Key information is summarised to inform practice.

Overview of attachment theory

Attachment theory, as proposed by John Bowlby and developed by others, has resulted in an evidence base for the essential premise that good emotional care in childhood and beyond is an important factor for later wellbeing. This is not a simple one-way process, and the individual's *attachment behavioural system* needs to work in conjunction with the primary carer's *caregiving behavioural system* in order for secure attachments to develop. Secure attachments in childhood are thought to lead to individuals developing a sense of themselves as acceptable, competent, and valued. As children become more independent they rely less on the physical presence of their caregivers, and instead utilise their internal working models of attachment to predict how others will respond to them. Realising that others also have their own needs, they negotiate a *goal-corrected partnership*.

A range of constitutional and environmental factors can affect the development of attachment relationships. Although 60 per cent of the general population develop Secure attachments, 10–15 per cent of children develop Avoidant strategies (not signalling their need for comfort to avoid rejection), and 8–10 per cent of children develop Ambivalent strategies (signalling distress at high frequency and amplitude to overcome intermittently available care). Many children (15–19 per cent) show signs of attachment Disorganisation, (where children become watchful and fearful, or 'frozen') where parental care is experienced as frightening. Research has linked (with some caveats) these categories of attachment responses in children to adult's current states of mind regarding their early attachment relationships. Avoidant, Secure, Ambivalent, and Disorganised classifications have been thought to correspond to Dismissing, Autonomous, Preoccupied, and Unresolved states of mind respectively.

Research has demonstrated that children who are not classified as Secure are more likely to show a range of cognitive and emotional deficits or delays and receive certain psychiatric diagnoses. In adulthood, a classification of Unresolved, Dismissing or Preoccupied states of mind is linked to many forms of distress and increased risk of being diagnosed with a psychiatric disorder.

Attachment and intellectual disabilities

Intellectual Disability does not preclude the development of Secure attachment relationships, although an ID may add challenges to the process. Children with Down's Syndrome have similar rates of Secure attachment to the general population, but may be more likely to show attachment Disorganisation when not Secure. Children diagnosed with Autism Spectrum Disorder (ASD) seem to achieve security in just over half of cases, but this is more likely in children with higher cognitive ability (implying that ID is a risk factor in itself in these children). An ID may increase the chance of disruption to caregiving

behaviours that promote security, and children with ID may be less able to manage emotional stressors by themselves, especially if attachment figures are less immediately available.

Some authors suggest that parental grief, loss and adaptation create a different pathway for the development of attachment behaviours; as the parents mourn the loss of the 'imagined' healthy child, the arrival of a child with an ID into the family evokes a 'grief reaction'. However, research suggests that most families adapt, possibly by being able to represent their child's actual abilities, rather than holding onto ideas of 'wished-for' abilities. Families may not identify their experience as a grief process and therefore to impose this would be unhelpful.

Being in receipt of life-long support may lead to difficulties in forming and maintaining attachments. Changes in placement, personnel, over-emphasis on 'personal independence', and boundary issues, may create particular challenges. However, research has demonstrated that using care staff as a *secure base-safe haven* is related to wellbeing and behavioural adaptation in adults with ID. People who live in paid care settings will differentiate their attachment behaviours across different carers, so that the behaviours that arise in each dyad will reflect individual relationships.

There are several challenges in the field of research into people with ID and attachment. There is as yet no gold standard assessment of attachment for people with ID, though the Adult Projective Picture System (AAP) may soon be fully validated. When using assessment tools, conceptual issues could lead to confusion about the use of 'attachment', particularly the use of 'attachment style' as developed in studies of adult romantic relationships. Psychologists should be very careful about the terminology and concepts that they use. Specific research studies on groups of people, some of whom have an ID (e.g. ASD or Down's Syndrome), may not be generalisable to the wider population.

Client and carer accounts

Two cases illustrate issues with attachment that are related to the person's experience of living with an ID, as well as other issues. Steve's experiences in his family demonstrate how his ID may have interrupted the development of attachment relationships in his family, which later led to difficult dynamics with well-meaning paid carers.

Carol's account demonstrated the importance of accepting and supporting her son Harry's expression of emotional distress over a long period of time. It also highlights the need for Harry's carers to provide a secure base by which he could explore his environment and achieve some independence, but also provide a safe haven for him when he was distressed.

Applying attachment in clinical practice

Guidance for practice is provided within the structure of assessment, formulation, intervention and consultation which will be familiar to psychologists.

Assessment is likely to involve multiple sources of information including detailed history taking, review of clinical records, interviews, observations, formal assessments and sometimes exploratory therapeutic sessions. Identification of factors that may suggest attachment difficulties will be included in any formulation, and specific questions to guide clinical interviewing are provided in recent publications and summarised here.

Formal assessment tools may be used by appropriately qualified psychologists. More sophisticated assessment tools with established construct validity may require further training and certification. 'Diagnosing' on the basis of anything other than standardised developmental assessments should be avoided.

Formulation should be consistent with the recent definition provided by the Division of Clinical Psychology (DCP) when formulating attachment difficulties. Hypotheses should be tentative and subject to change on the basis of new information, avoid labelling or stigmatisation, and respect the dynamic nature of attachment relationships. Formulations should be completed collaboratively when possible and should be based on the principle of attachment as an adaptive process.

Interventions following from formulations that suggest attachment difficulties may include psychological therapy, e.g. Disability Psychotherapy, Cognitive Analytic Therapy (CAT) or psychodynamic psychotherapy, for which there is preliminary evidence of effectiveness. Positive Behaviour Support (PBS), for people whose behaviour is perceived as challenging, may be tailored to address identified attachment difficulties. Integrative Therapy for Attachment and Behaviour (ITAB) may be considered for carers, if psychologists are able to access the training that has been developed by researchers in the Netherlands. Staff support and education (the CONTACT system) is a similar methodology which now has training materials. Both ITAB and the CONTACT system have promising evidence of change in actual attachment behaviours in carers and recipients of care, but require further validation. Finally, new interventions that have not yet been evidenced for people with ID may be applied, such as Video Interaction guidance (VIG), Circle of Security, Infant-Parent Psychotherapy, Developmental Dyadic Psychotherapy (DDP), and the Heijkoop method. It is important that psychologists develop the evidence base of all of these approaches if they use them.

Interventions should consider the number and quality of beginnings and endings in the lives of people with intellectual disabilities. The attachment issues that arise with multiple placement breakdowns, moves, and loss of carer relationships, should be raised and addressed where possible, as awareness is often low. The ending of any valued relationship, including those with the psychologists themselves, may require special attention.

Specific additional considerations

Attachment difficulties may arise, or be complicated by, a range of additional considerations.

Dementia is the subject of previous DCP Guidance. It suggests that psychological intervention may be necessary for people with dementia to enable family, carers and the client to feel as emotionally supported as possible. Earlier attachment difficulties are likely to be exacerbated by the dementia process, or emerge for the first time in adult life following diagnosis. Confusion and cognitive decline inherent in dementia may affect a person's internal working model so that they require physical proximity more than before to feel comforted and understood.

Autism Spectrum Conditions (usually associated with diagnosis of Autism Spectrum Disorder or ASD) can make a goal-corrected partnership difficult to achieve in some people, despite parents and others offering good responsivity. However, research indicates that individuals

with a diagnosis of ASD are able to develop Secure attachment relationships with primary caregivers. Interventions to support attachment relationships might include Social Stories™, social skills training or play-based therapies.

People with profound and/or multiple disabilities may require more physical proximity throughout their lives, and psychologists should promote the interpretation by carers of behaviours that may be attachment-directed rather than seeming to meet an auto-sensory function (simply to achieve food, etc.)

Parents with intellectual disabilities frequently lose care of their children following child protection concerns being raised. Recent studies have shown that parents with ID can learn or develop existing skills to improve their caregiving, though more research is required.

People who have an ID and who receive a *diagnosis of a personality disorder*, or have a *forensic history*, show similar rates of early deprivation, abuse and trauma as do other offenders. This means that psychologists can expect a higher rate of attachment difficulties in these clients, and they may be resistant to enhanced attempts to provide care, leading to a risk of frustration, rejection and hopelessness in individuals who might help. In these instances, a higher level of social support and therapeutic intervention may have to be provided than the person's adaptive skill set would seem to require.

The importance of clinical supervision in supporting emotional security is emphasised.

Consideration is also given to organisational factors which may present challenges to the operation of clinical services. When services attend to the needs of their staff then this is likely to have a positive impact on staff wellbeing and the quality of services offered.

Recommendations for research

A comprehensive survey of the attachment needs of people with ID in the United Kingdom is required to reduce the reliance on extrapolations from studies of people without ID. Assessment measures need to be further developed and validated for people with ID. Extending the attachment-informed interventions using video feedback methodologies developed in the Netherlands within the UK, would potentially replicate and support these as empirically based interventions.

Psychological therapies that explicitly target attachment relationships require controlled outcome studies to develop the practice-based evidence base. The present evidence consists of case studies and multiple case series, but the need for more controlled trials is a general need in the field of psychological therapies in people with ID. Finally, the attachment representations of psychologists themselves may have an effect on the outcome of interventions, as research into psychotherapy suggests this is important.

1. The need for this guideline

Attachment relationships and attachment theory are not a new phenomenon, they are central to all aspects of our lives. Attachment theory is explicitly applied to the health and social care of many groups, especially children. Difficulties in attachment have been linked to a wide range of problematic clinical outcomes in both children and adults. However, many clinicians and professional carers continue to experience uncertainty as to how to work in an attachment-informed way with people who have intellectual disabilities. In part, this may be due to a lack of information.

The aim of this guidance is to provide information about the attachment needs of people who have ID for psychologists working in health and social care services. It should inform their work with clients, families, organisations which provide services, and commissioners.

The document may be useful to other professionals who are working to promote good psychological support for people with ID.

The guidance includes:

- An overview of attachment theory with consideration of the particular needs of people who have intellectual disabilities.
- Factors to consider during:
  - assessment,
  - formulation, and
  - interventions.
- Additional considerations for the following areas of work;
  - behaviours that challenge others,
  - people with dementia,
  - people with a diagnosis of Autism Spectrum Disorder (ASD),
  - people with multiple and profound ID,
  - parents who have an ID,
  - people with a diagnosis of personality disorders or a forensic history
  - supervision and self-care of psychologists.
- Useful online resources.
- A proposed self-assessment tool.

2. Overview of attachment theory

2.1 What is attachment theory?

Attachment theory was developed by John Bowlby to explain the importance of the quality of early relationships between children and their primary caregivers. He proposed that both physical and emotional care were key components of early caregiving and that early separations and losses led to later development of psychological problems. Bowlby's work is presented as a complete theory in three classic texts[1 2 3], and initiated a wealth of research into children's attachment behaviours and their caregiver's responses which has led to a well-established evidence base in relation to children and adults who do not have intellectual or developmental disabilities.

Attachment theory proposes that the child's attachment behavioural system promotes physical proximity between the child and parent in response to actual or perceived 'threats'. This serves a protective function in order to aid the survival of the child. The perception of a threat leads to the child engaging in one or more attachment behaviours such as crying, holding arms out, or running towards the parent. The child's *attachment behavioural system* needs to work smoothly in conjunction with the parent's *caregiving behavioural system* in order for a secure attachment relationship to develop. This means that the child's attachment signals are noticed, understood and responded to promptly in a sensitive and consistent manner. Children whose parents miss their cues or offer an insensitive, inconsistent or rejecting response adapt their attachment behaviours accordingly to best meet their attachment needs. Thus many children develop organised strategies (known as insecure strategies) which enable them to stay close to their parent without risking rejection or further distress.

Bowlby proposed that children develop internal working models of attachment based on their day to day experiences with their caregiver regarding 'who his attachment figures are, where they may be found and how they may be expected to respond'[2]. He suggested that a key issue for children is whether they develop an internal working model of their 'self' as being acceptable, competent and valued. This will relate to experiences of a caregiver who is predictably comforting and emotionally available when needed and also supportive of the individual's exploration. Where these responses have not been consistently available, Bowlby stated that the child is at risk of developing a sense of self as 'incompetent' and 'unacceptable to others', which leads to poorer outcomes psychologically.

As children grow older and are less in need of direct physical proximity to their parents, they begin to rely on their internal working models (IWM's) of attachment to predict how others might respond to them. It is thought that this typically happens at around 1 to 3 years of age whilst the child's language and motor skills are rapidly developing. At this stage children may begin to understand that their caregivers also have needs, and to be able to negotiate a 'goal-corrected partnership'[4]. The goal-corrected partnership

1 Bowlby, J. (1969) *Attachment and Loss. Vol 1. Attachment.* London: Pimlico.
2 Bowlby, J. (1973). *Attachment and Loss. Vol 2. Separation – Anxiety and Anger.* London: Pimlico.
3 Bowlby, J. (1980). *Attachment and Loss. Vol 3. Loss.* London: Pimlico.
4 Bowlby, J. (1980). *Attachment and Loss. Vol 3. Loss.* London: Pimlico.

strengthens the attachment relationship through a process of continual review and modification of behaviours which have been previously been unsuccessful in meeting the child's attachment needs.

Four attachment classifications have been defined in young children through assessment systems such as the laboratory based Strange Situation[5]. These are Avoidant, Secure, Ambivalent and Disorganised. The strange situation used a laboratory based environment to observe and classify children's responses to a series of separations and reunions with their caregiver. The resulting classifications have been studied extensively and found to link with specific patterns of caregiving behaviours in family home environments, thus providing ecological validity. For example, a meta-analysis of 2000 parent-infant dyads found a distribution of attachment classifications consistent with the distribution predicted by Ainsworth and colleagues.[6]

Avoidant – Children who are classified as Avoidant (10–15 per cent of the general population) maintain proximity to their caregiver by apparently 'self-managing' and not signalling a need for comfort, thereby avoiding rejection.

Secure – Children who are classified as Secure (60 per cent of the general population) are reported to experience their caregiver as a 'secure base' from which to explore and a 'safe haven' to return to for comfort when distressed. They are confident that their attachment needs will be met and return quickly to explore and play once they have been comforted.

Ambivalent – Children who have an ambivalent attachment (8–10 per cent of the general population) will maintain proximity to the caregiver by extensive use of attachment behaviours, which may be of high amplitude, and it may become difficult to reduce arousal levels at times of distress.

Disorganised – Where children's attachment behaviours are classified as Disorganised (15–19 per cent of the general population[7]) it is reported that children experience their parents as either frightening or behaving in frightened ways. During the strange situation children with a Disorganised classification seemed to experience a dilemma. They sometimes showed fear/apprehension when approaching their parent which led to them 'freezing'. They were also reported to appear confused and disorientated. These behaviours may be noted in children who also exhibit organised strategies (both secure and insecure) on the strange situation, leading to an additional classification of Disorganised as well as another classification.

Such Disorganised patterns of behaviour are frequently observed in children who have been maltreated (Main & Solomon, 1986). In addition children may also experience distress related to having parents with substance misuse, mental health problems and/or unresolved trauma regarding historical abuse and loss. Disorganised attachment is strongly linked to later negative outcomes for the child regarding increased distress, stress, dissociative and aggressive behaviours[8].

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5 Ainsworth, M.D., Blehar, M., Waters, E. & Wall, S. (1978). *Patterns of Attachment: A Psychological Study of the Strange Situation.* Hillsdale, New Jersey: Lawrence Erlbaum.

6 Van Ijzendoorn, M.H. & Kroonenberg, P.M. (1988). Cross-cultural patterns of attachment: A meta-analysis of the strange-situation. *Child Development,* 59, 1, 147–156.

7 De Wolff, M.S., van Ijzendoorn, M.H. (1997). Sensitivity and attachment: A meta-analysis on parental antecedents of infant attachment. *Child Development*, 68, 571–91.

8 Van Ijzendoorn, M.H., Schuengel, C. & Bakermans-Kranenburg, M.J. (1999). Disorganised attachment in early childhood: Meta-analysis of precursors, concomitants, and sequelae. *Development and Psychopathology*, 11, 225–249.

A child may have a secure attachment with one primary caregiver and an insecure one with another: these classifications always refer to a particular relationship. By contrast, adults are classified on the Adult Attachment Interview (AAI)[9] according to their state of mind with respect to attachment which emerges from their attachment history, and so the terminology used for adults is different. There is thought to be a correspondence between adult state of mind and childhood categories:

Child categories	Adult state of mind
Avoidant	Dismissing
Secure	Autonomous
Ambivalent	Preoccupied
Disorganised	Unresolved

Dismissing – On the AAI, Dismissing adults attempt to minimise the importance of attachment relationships and experiences. They may give brief and positive accounts of their family history which are either contradicted or unsupported by the content of their interview. They might also appear contemptuous or critical of their caregivers whilst stressing their own independence and ability to cope.

Autonomous – Autonomous adults will present as valuing of attachment relationships whilst being able to remain realistic and objective regarding their past experiences and relationships. They are able to speak coherently and to freely explore their views of their relationships and past. They also seem realistic about their own imperfections as well as those of their caregivers.

Preoccupied – Preoccupied adults present as confused and non-objective in their narrative on the AAI. They appear preoccupied with past family relationships and may present as passive and childlike, overwhelmed or conflicted and angry. During the interview they may refer to their current relationships with caregivers when being asked questions about the past. Interviews may be longer in length due to adults providing longer and more involved answers to the questions.

Unresolved – An Unresolved classification refers to previous experience of attachment related trauma such as loss or abuse from caregivers. The adult has not been able to reconcile or resolve the trauma in their current state of mind and this is indicated by unusual speech. An example of this might be talking as if a dead person is still alive. The adult may report having ongoing feelings of guilt or responsibility where there is no objective reason for this.

2.2. Attachment difficulties and later outcomes

A large body of evidence links problematic early attachment relationships to personal difficulties in childhood, adolescence and adulthood. In children without ID, the following are associated with insecure or disorganised attachment classifications:

- Less persistence in problem solving in preschool children
- Poorer theory of mind as children enter school

9 George C., Kaplan, N. & Main, M. (1985). *The Adult Attachment Interview.* Unpublished Manuscript, University of California at Berkeley

- Poorer recall of life events at age 11
- Difficulties in relationships with peers & associated low self-esteem
- Increased risk of receiving a psychiatric diagnosis (e.g. Reactive Attachment Disorder, Oppositional Defiant Disorder, Conduct Disorder)

In adults without ID, individuals who do not have an autonomous (Secure) state of mind are reported to be at increased risk of psychological distress including paranoia, distressing intrusive thoughts, depressive thoughts and feelings, and are more likely to receive formal psychiatric diagnoses including Depression, Obsessive-Compulsive Disorder, Schizophrenia, and a range of personality disorders. Some research also links diagnosis of eating disorders to attachment difficulties.

Appendix 1 gives more detail of mainstream research with key references and the level of evidence indicated.

This section has offered an overview of attachment theory including terminology and the classifications which are commonly used in the gold standard attachment assessments validated for non-ID populations. The next section considers attachment specifically in the context of the lives of people with intellectual disabilities and their families and carers.

Key points: Overview of attachment theory

- Attachment theory was developed by Bowlby to explain the importance of the primary caregiver offering both physical and emotional protection to their child to increase chances of survival.
- The strange situation procedure was developed by Ainsworth and colleagues which later led to four commonly used classifications of attachment in children: Avoidant, Secure, Ambivalent, Disorganised.
- Secure attachment relationships develop in the presence of parents who consistently notice their child's attachment signals, understand them and respond promptly in a sensitive and consistent manner.
- Children whose parents miss their cues or offer an insensitive, inconsistent or rejecting response adapt their attachment behaviours to develop strategies (known as insecure strategies) which enable them to stay close to their parent without risking rejection or further distress. Children who experience consistently frightening care experience a breakdown or 'disorganisation' of attachment strategies.
- Children typically develop 'goal-corrected partnerships' after three years of age with their primary caregivers where they learn that their caregivers have needs too which need to be balanced with their own attachment needs to get the best outcomes.
- Children later rely on internal working models (based on their learnt experiences) to predict how others will relate to them.
- Attachment strategies need to be constantly reviewed and updated in relation to the person's context.
- A history of problematic attachment strategies are associated with a range of childhood and adulthood psychological problems.

3. Attachment and intellectual disabilities

Evidence suggests that attachment relationships are important for individuals with intellectual disabilities. However, parents and caregivers may face particular challenges when caring for an individual with an intellectual disability. This is because, despite their best efforts to protect and care for them, the disability or health condition does not change. This can potentially lead to distress and disruption in the attachment and caregiving systems.

3.1 Attachment classifications in intellectual disabilities

Some studies suggest that the proportion of attachment security is broadly equivalent between people with and without ID[10] . Research has reported that where children with Down's Syndrome (DS) are classified as having insecure attachment, they are disproportionately more likely to be classified as Disorganised, at rates similar to children without ID who have been maltreated, traumatised, or institutionalised[11]. The study suggested that parents of children with DS may find it harder to read their child's emotional signals, and that this may lead to difficulties understanding and responding to attachment cues.

In a meta-analytic review of 16 studies using the Strange Situation in children diagnosed with ASD, just over half of the children (53 per cent) were classified as Secure. There was variation across samples in levels of ID. This meta-analysis suggested that attachment Disorganisation was more likely in those children who had a greater degree of ID, suggesting that ID was a bigger risk factor for attachment Disorganisation than ASD alone[12].

The presence of ID may increase the risk of disruption to caregiving behaviours that promote security[13]. In addition 'fright without solution' may be more likely in children with ID due to a reduced ability to manage emotional stressors by themselves coupled with a potential lack of available attachment figures to gain support from[14].

3.2 Cognitive effects on reciprocity in children with Down's Syndrome

Research into attachment and ID has attempted to explore the relationship between cognitive impairments and attachment behaviours to explore whether the impairment has a direct effect on attachment classifications. A study of infants with Down's Syndrome suggested that children showed delay in emotional expression, with more 'blunted' responses, which made it more difficult for the adult carer to adequately interpret the meaning of the behavioural signals[15].

10 Larson, F., Alim, N. & Tsakanikos, E. (2011). Attachment style and mental health in adults with intellectual disability: Self-reports and reports by carers. *Advances in Mental Health and Intellectual Disabilities 5*, 15–23.

11 Schuengel, C., de Schipper, J.C., Sterkenburg, P.S. & Kef, S. (2013). Attachment, intellectual disabilities and mental health: Research, assessment and intervention. *Journal of Applied Research in Intellectual Disabilities*, 26, 34–36.

12 Rutgers, A.H., Bakermans-Kranenburg, M.J., van Ijzendoorn, M.H. & van Berckelaer, I.A. (2004). Autism and Attachment: A meta-analytic review. *Journal of Child Psychology & Psychiatry*, 45, 6, 1123–1134.

13 Marvin, R.S. & Pianta, R.C. (1996) Mothers' reactions to their child's diagnosis: Relations with security of attachment. *Journal of Clinical Child Psychology 25,* 436–445.

14 Schuengel, C. & Janssen, C.G.C. (2006) People with mental retardation and psychopathology: Stress, affect regulation and attachment; A review. *International Review of Research in Mental Retardation*, 32, 229–260.

15 Cicchetti D. & Serafica F.C. (1981). Interplay among behavioural systems: illustrations from the study of attachment, affiliation, and wariness in young-children with Downs syndrome. *Developmental Psychology*, 17, 36–49.

3.3 Parental grief, loss and adaptation

Parents commonly experience distress on learning that their child has a disability or chronic health condition[16]. Marvin and Pianta (1996) described this as a grief reaction which requires a process of adaptation and resolution. Bowlby wrote extensively about grief processes following the loss of a loved one. Marvin and Pianta[17] suggested that his theory was relevant whether the parent was grieving an actual loss or an imagined loss of the 'healthy child' they had expected to arrive. Parents who find it difficult to accept the reality of their child's condition may continue to search for a reason or alternate diagnosis as part of the grieving process. They may also feel responsible for causing their child's disability even if doctors have informed them that this is not the case.

Parents whose children have ID may also need extraordinary sensitivity to overcome the difficulty that their children have with expressing their attachment signals[18]. In addition, if parents are not able to develop an internal representation of their child's actual abilities rather than the *wished for abilities*[19] then this may impede their ability to parent sensitively and develop a secure attachment with their child[20].

Despite the considerable challenges reported by families, it is important to note that the majority of families adapt to their child's disability, 'resolving' their initial grief and loss. Experiences of recent family stress and levels of social support from family members appear to be important for parents who present as unresolved in relation to their child's intellectual disability[21]. However, each family culture is unique and the idea of loss or grieving in relation to their child's disability may not always be relevant or helpful for parents.

3.4 Specific risks related to receiving life-long support

Many individuals with ID receive life-long support from paid carers throughout their education, home living environments and day services. In addition to this, individuals may also receive care from a number of health and social care professionals meaning that a large network of people will be involved in a person's care at any one time. This poses particular risks to the psychological wellbeing, emotional safety and quality of care of people with ID due to:

- frequent changes of staff personnel
- high workload of staff
- discontinuity in staff presence
- limited opportunities for individual support

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16 Waisbren, S.E. (1980). Parent's reactions after the birth of a developmentally disabled child. *American Journal of Mental Deficiency, 84*, 345–351.

17 Marvin, R.S. & Pianta, R.C. (1996) Mothers' reactions to their child's diagnosis: relations with security of attachment. *Journal of Clinical Child Psychology*, 25, 4, 436–445.

18 Schuengel, C. & Janssen, C. (2006). People with mental retardation and psychopathology: stress, affect regulation, and attachment. *International Review of Research in Mental Retardation*, 32, 229–260.

19 Barnett, D., Clements, M., Kaplan-Estrin, M. & Fialka, J. (2003). Building new dreams: Supporting parents' adaptation to their child with special needs. *Infants and Young Children, 16*(3), 184–200.

20 Atkinson, L., Chisholm, V.C., Scott, B., Goldberg, S., Vaughn, B.E. & Blackwell, J. (1999). Maternal sensitivity, child functional level and attachment in Down syndrome. *Monographs of the Society for Research in Child Development*, 64, 45–66.

21 Fletcher, H. (2016). Attachment relationships between parents and their children: The impact of 'The Loss of the Healthy Child'. In H. Fletcher, A. Flood & D. Hare *Attachment in Intellectual and Developmental Disability: A Clinician's Guide to Practice and Research.* New York: Wiley.

- organisational cultures which value service users' development of independence from staff rather than the mutual interdependence which is observed in typical attachment relationships
- lack of support for paid carers in negotiating relationship boundaries with service users who have a limited social network

Research suggests that using direct-care staff as a 'secure base-safe haven' is positively related to wellbeing and behavioural adaptation[22] [23] [24]. Clegg and Sheard[25] suggested that clients in paid care settings will differentiate their attachment behaviours across professional caregivers indicating that each attachment relationship is specific to the relationship dyad and not part of a more general presentation of behaviours. These findings were also supported by a larger study of people with ID in day care settings[26]. While staff turnover in paid care settings is high and generally considered to be problematic in relation to quality of care[27], currently there is a paucity of research evidence linking this to client wellbeing.

'Quality management systems and institutional culture may selectively reinforce care patterns associated with insecure, dismissing attachment, while failing to reward the positive contribution that sensitive, affectively attuned caregiving makes to wellbeing of persons with disabilities.'

People who need people: Attachment and professional caregiving. Schuengel et al.[28]

3.5 Challenges to research into attachment and ID

3.5.1 Assessment tools

At present there is no measure of attachment which has been empirically validated for use with adults with ID, and leads to reliable and valid classification. Research into attachment and ID uses a variety of assessments which may be tapping different psychological constructs and this presents challenges to those interpreting the data. It is important not to confuse research into attachment 'styles' using self-report methods focusing on romantic adult relationships, with research that explores the internal working model of attachment using assessments such as the Adult Attachment Interview (AAI)[29] and the Adult

22 Clegg J. & Sheard C. (2002). Challenging behaviour and insecure attachment. *Journal of Intellectual Disability Research*, 46, 503–506.
23 De Schipper, E.J., Marianne Riksen-Walraven, J. & Geurts, S.A.E. (2006). Effects of child–caregiver ratio on the interactions between caregivers and children in child-care centers: An experimental study. *Child Development*, 77, 861–874.
24 De Schipper, J.C. & Schuengel, C. (2008). Less secure attachment behaviour to specific caregivers is associated with maladaptive behaviour in day care. *Journal of Intellectual Disability Research*, 52, 726–726.
25 Clegg J. & Sheard C. (2002). Challenging behaviour and insecure attachment. *Journal of Intellectual Disability Research*, 46, 503–506.
26 De Schipper, J.C. & Schuengel C. (2010) Attachment behaviour towards support staff in young people with intellectual disabilities: associations with challenging behaviour. *Journal of Intellectual Disability Research*, 54, 584–596.
27 Buntinx, W. (2008) The logic of relations and the logic of management. *Journal of Intellectual Disability Research*, 52, 588–597.
28 Schuengel, C., Kef, S., Damen, S. & Worm, M. (2010). People who need people: Attachment and professional caregiving. *Journal of Intellectual Disability Research*, 54, Suppl 1:38–47.
29 George, C., Kaplan, N. & Main, M. (1985). *Adult Attachment Interview.* Unpublished manuscript, University of California, Berkeley, USA.

Attachment Projective Picture System (AAP)[30]. There are no reported studies using the AAI with people with ID, probably due to the high level of verbal ability required. Nevertheless, the AAP has been successfully used with individuals with ID in pilot studies with promising results[31]. Research to validate the AAP for use with people with ID is ongoing[32].

The utility and limitations of assessment tools is discussed more fully in section 5.1 below (Assessment).

3.5.2 Terminology and concepts

Schuengel et al.[33] describe the different terminology and phenomena which attachment researchers may describe or purport to be measuring in their research. These include:

- **Behaviours:** the seeking and maintaining of proximity to achieve protection & support; e.g. proximity seeking, contact maintaining, avoiding, resisting, disorganisation of these.
- **Relationship:** description of the dyadic history of attachment behaviour and response.
- **Bond:** affective concern with a relationship perceived as stable, including desire for contact, dislike of separation and the need for comfort during separation.
- **Representation:** unconscious internal rules relating to attachment; e.g. coded as: Dismissing, Autonomous, Preoccupied, Unresolved.
- **Style:** the internal judgement that one feels comfortable getting close to others, and depending on them, or not; comfortable with intimacy and autonomy (secure), preoccupied with relationships, dismissing of intimacy and fiercely independent, or fearful of intimacy and actively avoidant[34]. See section 3.4.1 regarding the use of the term 'style' in attachment assessment.
- **Disorder:** specific patterns of atypical behaviours in the context of pathogenic care; inhibited, withdrawn, or indiscriminately social[35].

A sufficient understanding of the different concepts and terminology used in attachment focused research is required in order to effectively incorporate attachment theory into everyday practice. It is possible that the complex and multiple terminologies act as a barrier to attachment being confidently utilised by clinical psychologists.

3.5.3 Generalisability

There are a number of factors to consider when interpreting the evidence base. A significant proportion of the studies focusing on attachment and ID have been carried

30 George, C. & West, M. (2012). *The Adult Attachment Projective Picture System.* New York, NY: Guilford Press.
31 Gallichan, D.J. & George, C. (2014). Assessing attachment status in adults with intellectual disabilities: The potential of the Adult Attachment Projective Picture System. *Advances in Mental Health and Intellectual Disabilities, 8*(2), 103–119.
32 Gallichan, D.J., & George, C. (2014). Assessing attachment status in adults with intellectual disabilities: The potential of the Adult Attachment Projective Picture System. *Advances in Mental Health and Intellectual Disabilities, 8*(2), 103–119.
33 Schuengel, C., de Schipper, J.C., Sterkenburg, P.S. & Kef, S. (2013). Attachment, Intellectual Disabilities and Mental Health: Research, Assessment and Intervention. *Journal of Applied Research in Intellectual Disabilities*, 26, 34–36.
34 Bartholemew, K. & Horowitz, L.M. (1991). Attachment Styles among young adults: A test of a four-category model. *Journal of Personality & Social Psychology*, 61, 226–224.
35 Minnis H., Reekie J., Young D., O'Connor T., Ronald A., Grayand A. & Plomin R. (2007) Genetic, environmental and gender influences on attachment disorder behaviours. *British Journal of Psychiatry*, 190, 490–495.

out with children who have Down's Syndrome, and therefore the results may not be generalisable to children with ID who do not have DS. In addition there may be difficulties in classifying the attachment behaviours of children with ID due to the ambiguity about the reasons for their observed behaviour. This may reflect the ID itself, physical conditions associated with the ID, or communication difficulties, rather than the attachment behaviours *per se*.

In summary, there is an emerging evidence base pertaining to attachment in people with ID, which indicates that it is a valid and important phenomenon to study and incorporate into clinical work. The next section focuses on the stories and experiences of clients and carers, including their testimonials.

Key points: Attachment and intellectual disabilities

- Attachment relationships are important for people with ID. There is no current research to suggest that attachment strategies differ significantly between people with ID and the general population
- Parents of children with ID may experience a number of challenges to developing secure attachment relationships including emotional distress, difficulty understanding the child's communications and developmental level and increased levels of stress. These may influence the sensitivity of their responses.
- Each family culture is unique and ideas of loss and grieving in relation to disability may not always be helpful or relevant. Therefore clinicians need to be mindful not to make assumptions and to offer an individually tailored approach.
- Being in receipt of life-long support may pose particular risks to the psychological wellbeing, emotional safety and quality of care of people with ID due to frequent changes of staff, overload of work and limited opportunities for individual support.
- There are some significant challenges to conducting and interpreting research in attachment and ID. These include the lack of valid and reliable assessment tools, the range of different terminology used and problems with generalisability. It is important to be aware that the literature may be referring to separate constructs as 'attachment'.

4. Client and carer accounts

Illustrative client and carer accounts are included here to demonstrate how attachment issues may present in practice. While attachment issues are not the only factors determining the symptomatic and personal outcomes for both Steve and Harry, they are an important part of the accounts given.

4.1. Client account: Steve[36]

Steve is a 24-year-old man who accesses specialist learning disability services. His cognitive profile is very mixed, with low average verbal comprehension offset by clinically significant difficulties in perceptual skills, working memory and speed of processing information. Throughout his development, Steve's language skills were interpreted as predictive of his other skills. This seems to have created a negative feedback process at home and during his time at school.

He was referred to the community learning disability team for a course of psychological therapy at the age of 21 which addressed anxiety and related symptoms, but also raised longstanding issues of ambivalence towards his family members. Initially, he wished to remain living with them, but the family stated that this was very stressful for them because he would follow them around the home, resisted separation from his mother, and was very anxious about being asked to remain at home alone. This seemed to worsen as he left school and became an adult. Attempts at manualised 'anxiety management' were not successful and indeed, being asked to do these tasks by his family led Steve to either protest by shouting or swearing, or acquiesce, and then to sit on his own and start to cry. The family's perspective was that they had spent a lot of time trying to promote self-esteem and independence, but that on learning steps of a task, Steve would not do the task independently; it would lead to a 'mess' or a breakage, or he would want the other person to do it for him.

A high risk incident at home led the family to ask the local authority to find an independent living placement. This placement was highly individualised and supported, with a strong ethos of personal empowerment and independence through the learning of key living skills. Steve soon started to have difficulties with particular members of staff, with flashpoints based around new learning tasks where he was meant to develop personal and domestic living skills in order to move to less supported accommodation in future.

Steve's formulation suggested that his cognitive difficulties had interacted with a family situation where both parents had to work and sometimes had other major challenges. Steve and others would expect him to be successful at learning tasks, only to find these more difficult than expected, even when supported by others. It was as though he built all of the parts of the particular joint task, but could not put these together and do them on his own. This would often seem like a matter of choosing not to do something, or wanting the other person to do it for him. Steve became increasingly avoidant of new learning tasks and could become hostile if confronted with a task that was cognitively effortful, such

36 Steve (not his real name) wishes to remain anonymous. He gave his express consent to the wording of the section that is relevant to him.

as learning independence skills. Sometimes, Steve would state that he was a 'superhero' and had special powers, which may have helped him compensate emotionally for feelings of failure or where he felt criticised for a mistake.

A referral to the psychology team was made, for support with problematic behaviours such as shouting and swearing at staff. It was noted by the psychology team that only particular staff experienced difficulties of this kind.

An initial psychology–led workshop with carers led to a formulation identifying some key factors in Steve's presentation. While certain factors were associated with the behaviours, such as being explicitly corrected during a learning task, or when he wanted to buy items that could cause financial difficulty, it was the presence of particular staff that most consistently predicted an incident.

A series of further workshops with Steve and his team led to an understanding of what he found to promote his emotional security and decrease his reliance on hostile responses to make sense of his social world. There was an existing model of good practice with his key worker, Toni, who was able to model a method of correcting Steve without seeming to 'sharpen' her tone, or become overly directive. However, the relationship with two other members of staff had deteriorated to the point where they could not envisage working positively with Steve, and chose to end their work supporting him. This reflected an established vicious circle, where hostile responses from Steve led to attributions that he was disrespectful of these individuals, and in response, they would back off and speak to him more formally, sometimes avoiding him. Steve then perceived a lack of warmth in the working relationship, creating more anxiety and further feeding the spiral and breakdown of these bonds. Steve was genuinely mortified following any incidents where he expressed hostility, which also fed ongoing anxiety.

Steve's reports indicated that his carer's responses were sometimes perceived as austere and corrective when they were trying to be clear and direct, particularly where he was failing to learn independence skills. This resulted in severe anxiety and hostility, which was reported as incidents of 'verbal aggression and threatening others'.

Staff who were predictably warm, like Toni, had fewer difficulties and were able to support him to access the community successfully. The attunement, or the lack of attunement, therefore reflected both his preferences and his particular interpretation of well-meant responses, as well as the responses of staff, of whom some felt able to change their approach – by adopting a consistently warm tone and easy-going approach to the domestic skills that acted as trigger points – and some of whom felt they could not. Therefore, allowing for a degree of 'selection' of preferred carers can be beneficial for both parties and does not imply fault or blame.

Three questions were asked of Steve to elicit his views for the guidance:

Could you say how Toni helps when you have a difficulty?

It's really good. Toni and I get on great, I have no difficulties. She never tells me off, like [other staff member] makes me feel happy. She says 'oh I am glad I am working with you today, we have fun' [Steve smiles]… Toni is like a mam, when I have a problem, she helps sort it out.

What causes the difficulties?

Like when other staff make me feel stupid, [staff member]. Like when I went near the cooker, she says 'oi what are you doing, burn yourself, stop'. So I told her to [swears]. I apologised, I am sorry, I will be better… my behaviour is a disgrace. I told my mam by text. She came down and took me out for a bit, but I have to come back don't I?

What makes things better?

When Toni comes on. We have a laugh and do baking, I can do baking now. I make a mess and she laughs, and says 'no honey, like this'. When Toni's on I don't get stressed. I do my routine, but we go out, go swimming, have a laugh. Toni is great company.

Steve referred to his fear of being reprimanded, which he associated with earlier rejections, and his perception of the disappointment of others. He also showed how pleased he was to see Toni, whom he perceived to be understanding, reliable, and comforting at times of stress. Toni was able to engage Steve in activities that other staff members had refused to attempt due to perceived risks, such as Steve walking away from support staff or being stigmatised.

4.2 Carer account: Carol and Harry

Carol has had a long-term fostering relationship with Harry who has chronic epilepsy due to early brain damage. She was asked to discuss what are the most important features of caring for children like Harry, and what has been difficult.

'I've been a full time carer for this truly wonderful young man, this is some of our journey together. He arrived when he was 18 months old with a history of abuse involving physical attacks that were the likely cause of his learning difficulties. I was shocked to be told by a consultant that I should accept that he would be in a "vegetative state". My husband and I were determined that we would bond with him without regard for any disability.

For several very tough years, most of our parental relationship with Harry involved providing love and reassurance to him, physically and emotionally. He showed much screaming and frustration, which we took to be an expression of earlier emotional pain. It was as though we needed to let him know he was safe from harm now. Over time, this paid off; he learned to chew, smile, walk and talk. We learned Makaton to help our connection with him. There was respite support for us, which helped us cope. Though, I have always wondered why professionals in the health service talk "at" Harry, and don't form a real relationship with him. What are they afraid of?

He wasn't free from further trauma – some of his peers have sadly died, and members of his family also passed away. Harry has had periods of low mood, but this doesn't mean he is "ill", it just fits with his early and later losses. He is now in his 30s and doing brilliantly. You can see that people light up when he smiles at them. He has been able to express his feelings and his wondering about his parents – I have always felt that he should be able to express his feelings to us, never spare us by being compliant or "good".

I can't say for certain that our love, care and resilience in the face of great difficulties have been a major cause of his success. Services can be unresponsive, patronising, and avoidant; or they can be helpful and supportive. It's been way too variable.

But I look at Harry now, moving to living semi-independently in a group home (done carefully over a six month period), forming adult relationships, and having a romantic life, and with us now stepping back with mixed feelings as parents do when their children move out. He still has

weekends with us, and we meet up for a meal. Just like any parents and their adult child. I would say never write any child off – no child should be without protection, a parent who listens to their feelings, helps them cope with these, and helps them get out there and enjoy life.

My word for Harry is "brilliant".'

Carol's account makes very clear what the emotional needs of children with ID are, and that their carers need:

- to provide physical safety,
- to provide emotional safety and predictability,
- to offer emotional warmth consistently even (or especially) when the child presents in distress or anger,
- to take joy in the child and enjoy spending time with them,
- to provide shared exploration based on mutually enjoyable and rewarding activities and new learning.

Key points: Client and carer accounts

- Steve's account demonstrates the value he experiences in his relationship with a carer that is consistent, lighthearted and supportive of his needs.
- Steve's experience illustrates the differences frequently observed in relationships between individuals and different staff members.
- Staff were able to benefit from psychological intervention leading to an increased understanding of Steve's emotional needs, informed by his existing positive relationship with Toni.
- Carol's account about her life with Harry shows the importance of accepting and supporting his expression of emotional distress over a prolonged period of time.
- Services were reported to be variable in their response to Harry with some professionals being negative about Harry's future abilities and talking 'at' Harry and not forming a relationship with him.
- Carol's account emphasises the importance of primary caregivers providing emotional warmth and safety, consistency, predictability, mutual enjoyment and shared exploration in childhood.

5. Applying attachment in clinical practice

This section describes the ways in which attachment theory can inform the work of clinical psychologists. Drawing on the general evidence base and findings from studies of people with ID, the section is structured in terms of assessment, formulation, and intervention. In addition, specific clinical considerations are outlined.

5.1. Assessment

Psychological assessments will typically involve a range of approaches and data gathering in order to develop clinically useful formulations and interventions. Assessing attachment relationships is likely to require detailed history taking and review of clinical records, interviews and observations, formal assessments and individual therapeutic sessions which can explore attachment issues.

5.1.1 Identifying the need for attachment-informed work

During assessment, the following factors may indicate the need to draw upon an attachment-informed framework:

- Exposure to abuse and/or neglect,
- Early separations and school/placement breakdown,
- Hospital admissions for severe emotional or behavioural concern,
- Socioeconomic risks[37],
- Difficulties coping with transitions and ending relationships (e.g. saying goodbye to family/carers and ending work with professionals),
- Intense preoccupation with the whereabouts of attachment figures,
- Self-injurious behaviours,
- Onset or increase in challenging behaviours in response to loss,
- Reports of hostility between the individual and their support staff or carers,
- Previous diagnoses of mental health or personality disorder,
- Early parental death or experience of serious physical or mental health problems.

Psychologists should not assume that the above factors are necessarily associated with early attachment difficulties, as each individual responds to life events differently, depending on the resources available to them internally and externally. However, major life changes will naturally cause increased anxiety. Therefore an increase in attachment behaviours may serve an adaptive and protective function for the individual rather than indicating a clinical presentation which requires intervention. There may be a requirement for input to facilitate risk management of particularly challenging behaviours during periods of adaptation.

37 Cyr, C., Euser, E.M., Bakermans-Kranenburg, M.J. & Van Ijzendoorn, M.H. (2010) Attachment security and disorganization in maltreating and high-risk families: A series of meta-analyses. *Development and Psychopathology, 22*(1), 87–108.

5.1.2 Clinical interviewing

In order to effectively assess attachment, Fletcher[38] suggests that psychologists should consider the following in their assessments and clinical interviews:

- Parental reactions to their child's diagnosis and resolution of loss and grief,
- Family's culture and religious beliefs concerning disability,
- Experiences of early separations, losses or traumas of parents/carers,
- Intergenerational attachment experiences of parents/carers,
- Parent's mental health and emotional distress,
- Social support available to parents from their own families/support for carers within their teams,
- Parent-child interactions and attunement,
- Need for training for parents and carers to increase their understanding of attachment behaviours and identify helpful ways to respond (possibly using video to review their interactions).

One of the common difficulties in seeking this information with adults is that often the information is not available and the person themselves may not be able, or only partially able, to present their story. Perry and Flood[39] offer an additional set of questions focused on the current presentation of the individual which may help gather clinically useful information:

- How does the individual interact with the people around them?
- What expectations do they appear to have of those interactions?
- If supported by paid carers, how does the person respond to support staff beginning and ending shifts, taking absences from work, having sick leave, or leaving the job?
- Does the person show a strong preference for a particular caregiver? Does this cause any difficulties or concerns?
- How do they seek support from others during times of distress, anxiety or discomfort? Do individuals around them recognise these as support seeking behaviours?
- Does the person develop trust in those who support them and respond positively to reassurance in unfamiliar situations?
- How does the person respond to events which would be expected to be highly distressing for them – do they communicate an emotional response or appear outwardly unaffected?

In addition it is recommended that the individual's response to separating from and being reunited with relatives who have had primary caregiving roles is considered.

5.1.3 Formal assessment tools

Some commonly used formal assessments of attachment are summarised in Appendix 2 and 3. Information is provided as to whether the assessment is intended for use with children or adults, applicability to people with ID, the need for standardised training,

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38 Fletcher, H. (2016). Attachment relationships between parents and their children: The impact of 'The Loss of the Healthy Child'. In H. Fletcher, A. Flood & D. Hare. (2016). *Attachment in intellectual and developmental disability: A clinician's guide to practice and research.* New York: Wiley.

39 Perry, E. & Flood, A. (2016). Autism Spectrum Disorder and attachment: A clinician's perspective. In H. Fletcher, A. Flood & D. Hare. (2016). *Attachment in intellectual and developmental disability: A clinician's guide to practice and research.* New York: Wiley.

research or clinical function, the mode by which assessment is undertaken, and the conceptual focus of the tool.

Some aspects of formal assessment are problematic in people with intellectual disabilities. Psychologists should be aware that the instruments that have driven the seminal findings in research are highly sophisticated; the Strange Situation Procedure (SSP) and the Adult Attachment Interview (AAI) require rigorous training and certification before use, which therefore limits their use in routine clinical practice for the majority of psychologists. Given the issues of conceptual divergence in what is meant exactly by 'attachment', clinicians should exercise caution in interpreting the meaning of such instruments and avoid relying on one assessment tool.

While clinical psychologists are well placed to describe attachment behaviours in their clients and consider the strategies they use to maintain proximity to those close to them, categorical 'diagnosing' on the basis of limited information carries risks of misclassification and should be avoided.

Key points: Attachment in clinical practice

ASSESSMENT

- Assessing attachment relationships is likely to require a range of approaches including: detailed history taking, review of clinical records, interview, observations, formal assessments and individual therapeutic sessions.
- Certain factors may indicate the need to draw upon an attachment-informed framework e.g. a history of repeated placement breakdown, difficulty separating from primary caregivers and/or paid carers, preoccupation with the whereabouts of attachment figures, severe challenging behaviours.
- There may be an increase in adaptive and functional attachment behaviours following the experience of stressful life events.
- Clinical interviews should consider the person's early history as well as their current relationship patterns. This should include family culture, history of attachment relationships, current experience of social support and current stressors.
- Established valid assessments of attachment classification can only be used after rigorous training and certification. Other clinician based observations and rating scales may contribute usefully to clinical formulations and intervention, but caution is needed to prevent these being misinterpreted as a formal classification of attachment behaviours.

5.2 Formulation

The Division of Clinical Psychology has recently defined formulation in an information leaflet for clients who may see clinical psychologists in the UK[40], as follows:

'Formulation is a joint effort between you and the psychologist to summarise your difficulties, to explain why they may be happening and to make sense of them. It may include past difficulties and experiences if these are relevant to the present… The pieces of the "jigsaw" are pieces of information such as:

- *How you feel at the moment;*
- *What's going on in your life now;*
- *When the difficulties or distress started;*
- *Key experiences and relationships in your life;*
- *What these experiences and relationships mean to you.'*

It is important to ensure tentative hypotheses are constructed when using clinical judgement, history, or interpreting formal assessment measures. The psychologist should have a clear view of the psychometric basis of any scale or other tool used in relation to assessing attachment.

This definition of formulation is highly concordant with this guideline. Formulations should not apply an attachment 'label' to a particular person (X is 'clingy', Y is 'secure', Z is 'fearful') as this risks over-simplification of an individual's emotional life and actions, a failure to consider that attachment reflects and varies according to individual relationships[41], and stigmatisation.

Notwithstanding these cautions, the identification of potential or actual difficulties in attachment relationships in an individual formulation has a number of implications for any intervention or further assessment that is offered. The person may:

- find separation and loss more difficult,
- find it more difficult to benefit from interventions,
- blame themselves for losses,
- struggle to express their feelings (if they tend to dismiss their emotions),
- misidentify therapy for friendship or a potential sexual relationship,
- be more vulnerable to distress,
- find it difficult to make decisions that oppose parents or figures of authority,
- find the experience of meeting professionals upsetting or even frightening (if Unresolved state of mind is indicated),
- struggle to engage in a therapeutic relationship, or
- avoid help partially or completely.

Formulations should make clear that attachment strategies were developed as an adaptive response and identify cases where the individual's strategies are no longer current and appropriate (therefore requiring updating) versus those situations where the person's social context means that the attachment behaviours remain adaptive (and the environment or system of support needs adaptation).

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40 Division of Clinical Psychology, British Psychological Society (2015). *Working with a psychologist: Understanding Formulation.* www.bps.org.uk/dcp

41 De Schipper, J.C. & Schuengel C. (2010) Attachment behaviour towards support staff in young people with intellectual disabilities: associations with challenging behaviour. *Journal of Intellectual Disability Research*, 54, 584–596.

Formulations should ensure that the individual's developmental level is clearly described along with their current attachment strategies. Where families, staff or professionals present with expectations of independence which are developmentally inappropriate for the individual, this should be considered with the system and appropriate interventions planned. The interventions should be aimed at increasing awareness and understanding of the individual in their system of support and differentiate between functional independence and emotional independence.

It is recommended that psychologists include potential attachment factors within their formulations and explain the nature of attachment with their client in a supportive and non-blaming way when collaborating to produce their formulation.

Where joint formulations are more difficult (often where the ID is severe or profound), it is equally important to share a formulation that draws on attachment theory with the entire system of support.

Key points: Attachment in clinical practice

FORMULATION

- Attachment history should be included in individualised formulations.
- Formulations should make it clear that attachment strategies were originally developed as an adaptive response even where these strategies are identified as outdated and problematic in the individual's current context.
- The individual's developmental level should be clearly described along with their current attachment strategies within formulation. Where families or staff present with unrealistic expectations, this should be considered with the system and interventions planned to increase understanding of the individual's abilities and needs.
- Formulations should be shared with individuals and their system of support in a supportive and non-blaming way.
- Difficulties in attachment relationships may impact on the type of intervention and length of input needed for the individual and their wider system of support.

5.3 Interventions

Whilst it is not possible within this guideline to demonstrate the full range of psychological interventions that are available to people with ID[42], an overview is provided of selected approaches, which have focused on issues pertinent to both historic and current attachment relationships.

5.3.1 Psychological therapy

Psychological therapists strive to provide a safe and consistent therapeutic space to interact with the person with unconditional positive regard. They will engage in a joint learning

42 Division of Clinical Psychology, British Psychological Society (2016). *Psychological therapies and people who have intellectual disabilities*. Leicester, UK. BPS publications.

process, where the intention is for severe distress to decrease and/or to discover how to improve wellbeing.

There is not yet evidence that psychological therapies with a relational focus have any more or less success than psychological therapies which focus on symptom reduction and coping skills (e.g. mindfulness-based cognitive therapy). However it may be that the therapeutic relationship/alliance may account for much of the success of psychological therapy in people both with and without ID.

A particular approach, Disability Psychotherapy, developed and clearly summarised by Pat Frankish[43] and demonstrated in case studies[44], has the explicit goal of overcoming trauma and developing the individual's ability to develop attachments with and trust in others, which then improves their future experience of relationships.

Attachment theory has also been applied to Cognitive Analytic Therapy (CAT) with people with intellectual disabilities. A small pilot study[45] linked the reciprocal roles of 'overwhelming – overwhelmed' and 'unloving – unloved' to individual's previous experience of attachment relationships. Another initial study of 44 cases of psychodynamic psychotherapy suggests that clinicians may be able to determine which clients will have high initial symptom severity, and perhaps require more sessions, by rating client narratives on a 20-item scale and considering if these suggest secure or non-secure attachment representations[46].

Whilst little has been written about attachment theory in relation to other psychotherapeutic models for adults with ID, the theory is considered to be applicable whatever the approach being used, although research is required to confirm this.

5.3.2 Challenging behaviour and Positive Behaviour Support

Within Positive Behaviour Support (PBS) the individual's emotional and behavioural responses may be conceptualised in a way which overlooks the important function of these in terms of the individual's attachment relationships with others. For example, existing challenging behaviours may be helpfully formulated as a continued expression of Ambivalent attachment strategies which were adaptive during childhood. This would be in contrast to the more typical paradigm of focusing on cognition-emotion-behavioural responses[47]. Whilst this latter approach is practical and useful within PBS approaches, as well as evidence based, it may constrain the psychologist to see problems as 'factors' to be 'influenced' or 'altered', to the benefit of the client rather than recognising the mutual and interdependent attachment relationships which connect individuals and their caregivers.

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43 Frankish, P. (2016). *Disability Psychotherapy: Innovative Approaches to Trauma-Informed Care*. London: Karnac.

44 Frankish, P. (1989). Meeting the emotional needs of handicapped people: A psycho-dynamic approach. *Journal of Mental Deficiency Research*, 33, 407–414.

45 Psaila, C.L. & Crowley, V., 2006. Cognitive analytic therapy in people with learning disabilities: An investigation into the common reciprocal roles found within this client group. *Reformulation*, Winter, 5–11.

46 Skelly, A. & Burman, H. (2015). Forty-four worthwhile interventions: Clinician-rated attachment style and outcome of psychodynamic psychotherapy for people with intellectual disabilities. *Bulletin of the Faculty for People with Intellectual Disabilities*, *13*(1), 20–29.

47 Allen, D. (1999). Mediator Analysis: an overview of recent research on carers supporting people with intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research*, 43, 4, 325–339.

The purpose here is not to undertake a critical review of PBS but rather to support the integration of attachment theory within PBS. There are a number of ways in which this can be achieved:

- The NICE (2015) challenging behaviour guidelines are clear that family, environmental and developmental factors should be considered during initial assessment, prior to functional assessment.
- A mediator analysis should be completed, which takes into account the skills and availability of the network.
- Within Behaviour Support Plans, psychologists can promote the need for clients to be considered as persons with histories, and consider whether behaviours of concern reflect attachment related anxieties about separation and loss.
- There will also be a current 'constellation' of attachment relationships that require careful understanding. For example, if a member of paid care staff strongly reminds a person of an abusive parent, their working relationship may be unlikely to follow the same course as that of a staff member who reminds them of a loving and supportive parent.

How behavioural guidelines are implemented will vary according to such perceptions in an evolving way. There are attachment-based methods of working with 'behaviour' that allow the integration of these factors in a formal and systematic way[48] [49] [50], should practitioners wish to develop a method of working with behaviour where attachment is the primary focus.

However, the guideline recommends that when PBS is implemented, it includes clear and explicit accounts of past and current attachments and endeavours to promote:

- Ongoing stability in the physical environment and a minimisation of unnecessary moves, especially where these are based on service philosophy or ideas about 'independence' that are not consistent with the person's cognitive and emotional readiness for such moves,
- The physical, emotional and sexual protection of people with intellectual disabilities who may be vulnerable to abuse,
- Challenging disrespectful care especially where the carer withdraws positive regard in response to difficulties the person may demonstrate,
- Identifying and intervening where poor quality relationships are evident although physical needs may be being adequately met,
- Development of and learning from naturally-occurring attachment relationships where the carer is warm, predictable, and resilient to behaviours negatively affecting the relationship (as with Carol and Harry),

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48 Shackleton, A. (2016). Have a heart: Helping services to provide emotionally aware support. In H.K. Fletcher, A. Flood & D.J. Hare (Eds.) *Attachment in intellectual and developmental disability: A clinician's guide to practice and research.* New York: Wiley.

49 Skelly, A. (2016). Maintaining the bond: Working with people who are described as showing challenging behaviour using a framework based on attachment theory. In H.K. Fletcher, A. Flood, & D.J. Hare (Eds.) *Attachment in intellectual and developmental disability: A clinician's guide to practice and research.* New York: Wiley.

50 Schuengel, C., Clegg, J., de Schipper, J.C. & Kef, S. (2016). Adult attachment and care staff functioning. In Fletcher, H.K., Flood, A. & Hare, D.J. (Eds.) *Attachment in intellectual and developmental disability: A clinician's guide to practice and research.* New York: Wiley.

- Supporting participation, new activities and skills training by promoting mutual enjoyment,
- Supporting regular new learning that involves the person and the caring individual in joint venture,
- Promoting relationship building and maintenance as part of ongoing review of progress, e.g. in periodic service reviews.

None of these recommendations are inconsistent with PBS in any way but may not be the focus to date.

5.3.3 Integrative Therapy for Attachment and Behaviour (ITAB).

A specialist intervention was developed by Sterkenburg and colleagues in the Netherlands[51], initially reported as a single case and then a case series[52], in order to address challenging behaviours in children with multiple disabilities. The approach involves adding the development of an attachment relationship between therapist and child prior to engaging in behaviour modification. The authors suggest that the reinforcement from the positive relationship creates an advantageous set of contingencies during behaviour change, and allows the child to regulate their emotions more successfully. Importantly, the authors included a control condition where the relationship was not developed prior to behavioural intervention. On modifying the behaviour directly, the therapist then moves to support daily caregivers to develop secure relationships with the child as well, before withdrawing. This approach is an explicit method of augmenting behavioural approaches and the initial evidence suggests that it is an effective methodology that may be superior to behaviour modification provided by unfamiliar therapists. However, a study with more participants, random allocation to ITAB or control condition, and widening the approach to children without multiple disabilities, or adults with ID, would allow the findings to be generalised to other groups.

5.3.4 Staff support and education (The CONTACT system).

Another specific intervention involves specialised training, but seems to offer clear evidence of effectiveness. Damen and colleagues[53] developed the CONTACT intervention within group homes for children and adults with visual impairment and moderate to profound ID. In the system, professional caregivers refer a client whose relationship with them they consider to require improvement. The caregivers then review videotaped interactions with their client and are encouraged by a therapeutic coach to identify ways in which they could improve their relationship based on the principles of attachment theory as well as 'inter-subjectivity theory'[54]. A large group of 72 caregivers of 12 clients

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51 Sterkenburg, P.S., Janssen, C.G.C. & Schuengel, C. (2008) The effect of an attachment-based behaviour therapy for children with visual and severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21, 126–135.

52 Schuengel, C., Sterkenburg, P.S., Jeczynski, P., Janssen, C.G.C. & Jongbloed, G. (2009) Supporting affect regulation in children with multiple disabilities during psychotherapy: A multiple case design study of therapeutic attachment. *Journal of Consulting and Clinical Psychology*, 77, 291–301.

53 Damen S., Kef S., Worm M., Janssen M.J. & Schuengel C.(2011) Effects of video-feedback interaction training for professional caregivers of children and adults with visual and intellectual disabilities. *Journal of Intellectual Disability Research*, 55, 581–595.

54 Janssen M.J., Riksen-Walraven J.M. & Van Dijk J.P.M. (2003). Contact: effects of an intervention program to foster harmonious interactions between deaf-blind children and their educators. *Journal of Visual Impairment & Blindness*, 97, 215–229.

demonstrated that staff became more skilful at perceiving and responding to emotional signals from clients. The 'mutuality' – similar to the idea of 'attunement' – of the relationships demonstrably improved. Interestingly, although initially the caregivers' own attachment representations were associated with the quality of initial interactions between service users and carers, following intervention these differences were not evident. The study reported that there were in fact increased gains in quality of response for those carers classified as insecure versus the carers classified as autonomous secure[55]. Again, this is reason to be optimistic that carer's own states of mind regarding attachment do not preclude them benefitting from interventions focused on improving their responses to services users. Preliminary results suggest that challenging behaviour may be reduced where caregivers follow the modelled relationship skills[56], but further research is required. It has been acknowledged that this kind of training is costly and difficult to roll out on a national basis. However, manuals and DVDs have been produced that psychologists may wish to access to pursue this approach as a clinical intervention[57]. Practitioners in the UK may also consider training in interventions such as Video Interaction Guidance (see below), which has several similarities with the CONTACT intervention.

5.3.5 Interventions evidenced with other groups

A number of evidence-based interventions for children without ID may be appropriate for use in individuals with ID. These include Video Interaction Guidance (VIG)[58], Circle of Security[59], and Infant-Parent Psychotherapy[60]. These interventions have several commonalities involving psychoeducation about the child's attachment needs, development of sensitivity and attunement to the child's attachment behaviours, review using feedback (often video), and reflection on the parent's own attachment experiences and how these may exert an influence on their parenting. A meta-analysis found that these approaches tend to be more effective where they have sufficient numbers of sessions and a clear cut behavioural focus[61].

Dyadic Developmental Psychotherapy (DDP)[62] was developed for foster-parents of neglected or traumatised children and elaborated later with parents and families into attachment-focused family therapy. The approach draws on recent findings in the neuroscience of emotions[63]. The approach involves establishing an intuitive, non-verbal

55 Schuengel C., Damen S., Worm M. & Kef S. (2012). Attachment representations and response to video-feedback intervention for professional caregivers. *Attachment & Human Development*, 14, 83–99.
56 Van Wouwe H. (2012). Triple C: researching the effects of treatment. *Journal of Intellectual Disability Research*, 56, 683–683.
57 Sterkenburg P. S. (2012). *Developing Attachment: A Workbook for Building up a Secure Relationship with Children or Adults with Severe Intellectual or Multiple Disabilities*. Microweb Edu, Doorn, The Netherlands.
58 Kennedy, H., Landor, M. & Todd. L. (2010). Video Interaction Guidance (VIG) as a method to promote secure attachment. *Educational and Child Psychology*, 27, 3.
59 Cooper, G., Hoffman, K., Powell, B. & Marvin, R. (2005). The circle of Security intervention: Differential diagnosis and differential treatment. In L.J. Berlin, Y. Ziv, L. Amaya-Jackson & M.T. Greenberg (Eds.) *Enhancing Early Attachments: Theory, research, intervention and policy* (pp.127–151). New York: The Guilford Press.
60 Lieberman, A.F., van Horn, P. & Ippen, G.C. (2005). Toward evidence-based treatment: Child–parent psychotherapy with pre-schoolers exposed to marital violence. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44, 1241–1248.
61 Bakermans-Kranenburg, M.J., van IJzendoorn, M.H. & Juffer, F. (2003) Less is more: Meta-analyses of sensitivity and attachment interventions in early childhood. *Psychological Bulletin*, 129, 195–215.
62 Hughes, D.A. (2011). *Attachment-Focused Family Therapy: The workbook*. New York: W.W. Norton.
63 Fosha, D. Siegel, D.J. Solomon, M.F. 2009, *The Healing Power of Emotion*. New York: W.W. Norton.

'inter-subjectivity'. Practitioners adopt an 'attitude' of Playfulness, Acceptance, Curiosity and Empathy (PACE) which is intended to build emotional safety via the attachment caregiving system. A workbook involving video (using actors) is available. The focus on interactional 'co-regulation' of difficult or chaotic emotions, by altering the way parents or carers engage with the person, is intended to overcome difficult emotions and past traumatic reactions. Further research is needed to confirm if it is suitable for persons with ID.

Co-regulation of turbulent emotions through attuned relationships between 'Important Others' (parents and carers) and people with ID who are challenging is also a core feature of the Heijkoop method[64]. Again, this is a new approach for which detailed research has yet to emerge.

5.3.6 Beginnings, endings and working with other agencies

It is often the case that adults with ID will at some point need a service commissioned by their family and/or statutory services where a move from the family home to a paid care setting is required. This can occur in young adulthood at a chronologically appropriate time, on the death or decline in health of parents later in life, or indeed at any point in between. Occasionally it must be done as a matter of urgency.

Clinical psychologists can helpfully engage with colleagues who are identifying potential placements to ensure services are capable of providing warm, enduring attachments that are resilient to reduce the risk of placement breakdown. Psychologists should offer training to social care professionals and providers, introducing ideas of attachment theory to everyone in the person's system of support. Awareness that their support is crucial to the person's wellbeing is not always obvious to staff (or family carers) who may not be securely attached themselves, especially those who may demonstrate an attachment strategy which minimises the importance of attachment relationships and comfort from others[65].

Particular attention needs to be paid to the quantity and quality of endings in client-carer relationships. People with ID often have repeated endings with paid carers and professionals. They may move out of the family home at the point when their parents' health is declining or following loss of their parents. The person may need to express their emotional losses in their new relationships, whilst carers may be more focused on thinking positively about the future, creating a mismatch. Care plans should be developed to minimise further unnecessary losses, while carer relationships need to be responsive and supportive. Psychologists and other professionals should also consider the impact of the ending when finishing their interventions.

Whatever the reason for the ending, careful thought should be given as to how to say goodbye. Even when it is thought that further contact would be detrimental or impractical, a range of interventions can apply including:

- Planning a goodbye party,
- Taking photos for both to keep,

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64 Heijkoop, J. & Clegg, J. (2012) Introduction to the Heijkoop approach to challenging behaviour in ID. In: Ideas Exchange: Emerging Good Practice in ATU Intellectual Disability Specialist Services, 3 February, 2012, Nottingham, UK. (Unpublished).

65 Schuengel, C., Damen, S., Worm, M. & Kef, S. (2012). Attachment representations and response to video-feedback intervention for professional caregivers. *Attachment and Human Development*, 14, 83–99.

- Creating a social story[66] which explains the ending,
- Writing a goodbye letter or card to keep.

> *'A sense of availability, even if only in mind, is fundamental to autonomy in attachment'*
> John Byng-Hall[67]

5.4 Specific additional considerations

5.4.1 Dementia

There is little research or clinical guidance as to the attachment needs of people with ID who develop dementia. The Faculty's joint guidance with the Royal College of Psychiatrists[68] mentions the impact of abuse on apparent cognitive decline, the need for family and carers to be well informed about diagnosis, and potential psychological intervention to 'enable them to feel emotionally supported and begin to understand the diagnosis'. The confusion and cognitive decline inherent in dementia may affect a person's internal working model so that they require physical proximity more than before to feel comforted and understood.

Clinical experience and research in the broader field suggests the following implications in terms of the person's attachment relationships:

- Significant life events such as moving home or changes to daily routine can lead to deterioration in functioning which can mimic dementia,
- Loss of cognitive functioning may be associated with recent attachment related losses such as abuse and bereavement,
- Relationships with family, friends and significant others should be maintained throughout the person's progression of dementia,
- Moving in the later stages of the condition may increase disorientation and precipitate a decline in functioning,
- The person's need for physical proximity to others in response to perceived 'threats' may increase, leading to new behaviours of calling out, shouting, screaming and pulling people towards them,
- It is important for carers to understand that attachment relationships are life-long and of just as much importance in later stages of life as they are in earlier adulthood. For people with dementia who are disorientated and confused, a higher level of physical proximity and contact is needed in order to maintain the perception of emotional safety.

5.4.2 Autism Spectrum Disorders

Where parents of children diagnosed with ASD recognise their attachment signals and respond in an attuned way, secure attachment relationships will form. However, some children may have primary cognitive difficulties in developing 'Theory of Mind' which

66 Test, D.W., Richter, S., Knight, V. & Spooner, F. (2010). A comprehensive review and meta-analysis of the social stories literature. *Focus on Autism and Other Developmental Disabilities*, 26, 1, 49–62.

67 Byng-Hall, J. (2008). The crucial roles of attachment in family therapy. *Journal of Family Therapy*, 30, 129–146.

68 British Psychological Society/Royal College of Psychiatrists (2015). *Dementia and People with Intellectual Disabilities*. Leicester, UK: BPS publications.

make the 'goal-corrected partnership' difficult to negotiate, creating a rather one-sided dynamic. It has been proposed within the NICE Guidance in relation to Children's Attachment that behaviours that seem to denote insecurity could occur directly because of social communication difficulties associated with a diagnosis of ASD, even though parents offer good responsivity. Interventions therefore need to be informed by research into ASD (e.g. need for concrete concepts, avoiding terms that describe the mental states of others, such as 'know', 'want', 'believe', etc.), as well as research into attachment. Interventions may include Video Interaction Guidance (VIG) or similar, but also elements of ASD-specific interventions such as Social Stories™, social skills training and play based therapies.

5.4.3 People with multiple and/or profound disabilities

People with multiple/profound disabilities may require actual physical proximity at all times, both for survival and to ensure acceptable quality of life. Communication may be difficult to understand and behaviours of concern may be misinterpreted as intended to achieve tangible reinforcement (e.g. food, stimulation via activity) when the person is instead trying to initiate attachment directed behaviours. Interventions such as Intensive Interaction, Integrative Therapy for Attachment and Behaviour (ITAB) and the CONTACT programme have been developed specifically for people with multiple and profound learning disabilities and sensory impairment. They aim to support the development of reciprocal communication and mutually pleasurable interactions through non-verbal communication. Carers are helped to increase their ability to recognise the individual's cues and respond sensitively to these. Activities are created which are developmentally appropriate and of interest to the individual and choices are supported based on interpreting the individual's communications about when they want an activity or interaction to change or stop.

5.4.4 Parents with intellectual disabilities

Parents with intellectual disabilities are at increased risk of having their children removed[69]. There is little published research on developing positive attachment relationships and parenting skills in this area, although a video-feedback intervention targeting parental stress has recently been trialled[70] [71]. There is some evidence to indicate that individuals with intellectual disabilities are able to learn about parenting skills[72], although further research is needed.

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69 Booth T, Booth W, & McConnell D. (2005). The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts. *Journal of Applied Research in Intellectual Disabilities*, 18, 7–17.

70 Hodes, M.W., Meppelder, H.M., Schuengel C., & Kef, S. (2014). Tailoring a video-feedback intervention for sensitive discipline to parents with intellectual disabilities: A process evaluation. *Attachment & Human Development*, 16, 387–401.

71 Hodes, M.W., Meppelder, H.M., de Moor, M.H.M., Kef, S. &, Schuengel C. (in press, 2017). Alleviating parenting stress in parents with intellectual disabilities: A randomized controlled trial of a video-feedback intervention to promote positive parenting. *Journal of Applied Research in Intellectual Disabilities*.

72 Knowles, C., Machalicek, W. & Van Norman, R. (2015). Parent education for adults with intellectual disability: A review and suggestions for future research. *Developmental Neurorehabilitation*, 18, 336–348.

5.4.5 Diagnosis of personality disorder and/or forensic issues

Research is very limited in this field, though it is known that adults with ID who receive convictions and have a diagnosis of personality disorder show similar rates of early deprivation, abuse and trauma in childhood as do other offenders[73]. Since a diagnosis of a personality disorder is strongly associated with attachment difficulties in the general population, comprehensive history taking will be important where clients have a forensic history and ongoing interpersonal problems.

Individuals whose early experiences have resulted in a strategy of 'dampening down' their emotional and attachment needs may experience empathic responses from others as anxiety provoking. This appears to be related to fear of losing the emotional connection with that person[74]. The process of staff becoming more emotionally available to people with a diagnosis of personality disorder might not lead to the intended clinical improvements, potentially leaving staff frustrated that their attempts to offer comfort and containment are not valued. Therefore it is necessary for staff to have access to a psychological understanding of these complex relationships through supervision, training and opportunities for regular reflection.

Support services may need to offer more intensive and long-term intervention to establish sufficient physical and emotional safety that would keep the individual and their community safe. This may cause challenges for social care and continuing health care professionals in planning and securing a higher level of support than is practically needed for the individual's level of adaptive functioning (particularly for those people with mild or borderline intellectual disabilities who might not fit neatly into eligibility guidelines).

5.4.6 Supervision and self-care

Clinical supervision, which should be regular, needs to include time to reflect on attachment issues arising in the work of the psychologist. Clinical supervision, as with psychological therapy, is also a process that supports emotional security. It should ideally offer a safe space to share and organise difficult feelings, explore the psychological work creatively and promote a spirit of positive enquiry. As such, it is recommended as essential practice for all grades of clinical psychologist.

Maintaining consistent boundaries for psychotherapy and psychological interventions can be challenging when working with individuals who have complex or fluctuating needs relating to their attachment relationships. This can be further challenged by organisational factors which may reduce the clinician's confidence and feeling of security. These might include:

- Physical danger that may cause fear in the course of their work, e.g. lone working with clients who have a history of aggression and violence,
- Emotional insecurity that may result from insecure working conditions (e.g. hot desking) and the lack of a secure physical base (e.g. a room to see people in regularly),
- Noisy, disrupted or otherwise unsuitable work environments;

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73 Steptoe, L., Lindsay, W.R., Finlay, C. & Millar, S. (2016). Attachment, Personality Disorder and offending: Clinical implications. In Fletcher, H.K., Flood, A. & Hare, D.J. (Eds.) *Attachment in Intellectual and Developmental Disability: A Clinician's Guide to Practice and Research.* New York: Wiley.

74 Liotti, G. (2011). Attachment disorganisation and the clinical dialogue: Theme and Variations. In Solomon, J. & George, C. (Eds.) *Disorganised Attachment and Caregiving.* New York: Guilford Press.

- High levels of exposure to people in crisis without sufficient means to offer support and resolve such situations,
- Poor or limited supervision arrangements,
- Working cultures that are dismissing of staff distress,
- Organisations which respond to external pressure by increasing demands on staff,
- A lack of training that meets the needs of both the service and the psychologist,
- The availability of psychological support or confidential therapy for psychologists who require emotional support.

It is important for clinicians to identify the needs of the service users and themselves to support the provision of a consistent and stable service. When services attend to the needs of their staff then this is likely to have a positive impact on staff wellbeing and the quality of services offered.

Key points: Attachment in clinical practice

INTERVENTION

- Attachment theory can be incorporated into psychological interventions across a range of theoretical models.
- Approaches including Positive Behaviour Support, ITAB and CONTACT have reported promising findings in terms of improving people's quality of life and the quality of their relationships with others.
- A number of interventions have good evidence for children without ID which may be of future utility for individuals with ID including Video Interaction Guidance, Circle of Security, Infant-Parent Psychotherapy and Dyadic Developmental Psychotherapy.
- Transitions require careful thought and planning to support new beginnings and endings of relationships.
- Working with people who have additional considerations (such as dementia, ASD, profound and multiple ID, parents with ID and individuals with diagnoses of personality disorder) requires the ability to combine clinical knowledge relevant to the client group with an understanding of attachment theory. This means that formulation and clinical interventions can be individually tailored to best meet the needs of the person and their system of support.
- Psychologists should promote supervision and self-care that allows them to meet the attachment needs of the people with intellectual disabilities whom they work with. Occupational hazards, stress, and a lack of capacity to reflect on one's practice may make this more difficult.

This section has discussed the application of attachment within clinical practice across the broad spectrum of work carried out by clinical psychologists. The next section describes ideas for future research, followed by a list of useful resources and appendices.

6. Recommendations for research

Further research is required to explore a number of areas pertaining to the attachment needs of people with intellectual disabilities.

- A comprehensive survey of the attachment needs of people with intellectual disabilities is required. We do know that people with intellectual disabilities are at higher risk of sexual abuse[75], being removed from the family of origin, and living in multiple placements[76], but there is no comprehensive account of the likely attachment sequelae of these risks for the particular client group. NICE Guidance for children at risk of intervention to protect them from attachment difficulties[77] suggests that measuring parenting quality and sensitivity, multiple socioeconomic factors, and co-existing mental health problems all need to be quantified.
- There is a need for the further development and validation of assessment measures for people with a range of severity of ID. See Appendix 2 for a list of measures that are currently in use.
- Attachment informed interventions for families and paid carers show considerable promise and this work in the Netherlands now forms a substantial body of research for people with intellectual disabilities[78] [79]. Video feedback methodologies are recommended in the NICE guidance for children at risk of care proceedings, and are reported to be useful in persons with ID and those who care for them, in research from the Netherlands. We need UK-based research that replicates and extends these findings.
- We also require systematic studies of Disability Psychotherapy, exploring its effectiveness in helping individuals overcome trauma, and developing the ability to attach and trust in others, leading to success in later relationships. Controlled trials are possible and could use standardised outcome measurement tools as well as waiting list and follow up comparisons.
- The attachment representations of psychologists themselves could be investigated.

75 Turk, V. & Brown, H. (1993). The sexual abuse of adults with learning disabilities; results of a two-year incidence survey. *Mental Handicap Research*, 6, 13–216.

76 Schuengel, C.; Oosterman, M and Sterkenberg, P.S. (2009). Children with disrupted attachment histories: Interventions and psychophysiological indices of effects. *Child and Adolescent Psychiatry and Mental Health, 3*, 26, 1–10.

77 National Institute for Health and Clinical Excellence, (2015). Children's Attachment: Attachment in children and young people who are adopted from care, in care or at high risk of going into care. nice.org.uk/guidance/ng26.

78 Schuengel C., Damen S., Worm M. & Kef S. (2012). Attachment representations and response to video-feedback intervention for professional caregivers. *Attachment & Human Development*, 14, 83–99.

79 Damen S., Kef S., Worm M., Janssen M. J. & Schuengel C.(2011) Effects of video-feedback interaction training for professional caregivers of children and adults with visual and intellectual disabilities. *Journal of Intellectual Disability Research*, 55, 581–595.

7. Useful online resources

- Circle of Security website and animation:
  https://www.circleofsecurityinternational.com/animations

- An introduction to attachment and the implications for learning and behaviour:
  http://www.bathspa.ac.uk/education/research/attachment-aware-schools/importance-of-attatchment/ – an excellent resource with details of attachment theory and implications for learning and school environments for children in mainstream schools.

- MindEd e-learning – various brief training modules on attachment in non-ID populations (free to access):
  https://www.minded.org.uk/Search

- Association for Video Interaction Guidance UK website:
  http://www.videointeractionguidance.net/

- Intensive Interaction website:
  www.intensiveinteraction.org

- Information sheet on Attachment & Complex Learning Difficulties and Disabilities Research Project (CLDD):
  http://complexld.ssatrust.org.uk/uploads/attachment-info%20Aug.pdf

- Materials from the Amsterdam clinical research group can be purchased via this link:
  www.webedu.nl/bestellen/bartimeus

Appendix 1. Outcomes of non-secure and disorganised attachment in childhood and adulthood and an indicator of evidence quality

Outcomes of attachment insecurity or disorganisation		Key references	Level of evidence[80]
Childhood & adolescence	Less persistence in problem solving at age two	Meins, E. (1997). *Security of Attachment and the Social Development of Cognition*. Hove: Psychology Press.	P
	Poorer theory of mind at age 4-6 years	Fonagy, P.; Redfern, S. & Charman, A. (1997). The relationship between belief-desire reasoning and a projective measure of attachment security (SAT). *British Journal of Developmental Psychology*, 15, 51–63. Meins, E., Fernyhough, C., Russell, J.A. & Clark-Carter, D. (1998). Security of attachment as a predictor of symbolic and mentalising abilities: a longitudinal study. *Social Development*, 7, 1–24.	M
	Poorer recall of past life events at age 11 years	Main, M. (1991). Metacognitive knowledge, metacognitive monitoring, singular (coherent) vs. multiple model of attachment: findings and future directions for research. In Parks, C.; Stevenson-Hynde, J. & Marris, P. (Eds.) *Attachment Across the Life Cycle*. London: Routledge.	P
	Incompetence with peers & associated low self-esteem	Groh, A., Roisman, G., Booth-LaForce, C., Fraley, R., Owen, M. & Cox, M. (2014a). Stability of attachment security infancy to late adolescence. *Monographs of the Society for Research in Child Development*, 79, 51–66. Groh, A., Fearon, R.P., Bakermans-Kranenburg, M.J., van Ijzendoorn, M.H., Steele, R.D. & Roisman, G.I. (2014). The significance of attachment security for children's social competence with peers: a meta-analytic study. *Attachment & Human Development*, 16, 103–36.	P

80 (0-opinion only, P-preliminary or single study, M – multiple study, replications, or literature review, E – established by clinical practice or national guidance policies)

	Outcomes of attachment insecurity or disorganisation	Key references	Level of evidence
Childhood & adolescence	Diagnosis of Reactive Attachment Disorder (RAD)/Disorganised Attachment Disorder (DAD)	National Institute for Health and Clinical Excellence, (2015). Children's Attachment: Attachment in children and young people who are adopted from care, in care or at high risk of going into care. nice.org.uk/guidance/ng26.	E
	Diagnosis of Oppositional Defiant Disorder		E
	Diagnosis of Conduct Disorder		E
Adulthood	Proneness to paranoia/ diagnosis of schizophrenia	Sitko, K., Bentall, R., Shevlin, M., O'Sullivan, M. & Sellwood, W. (2014). Associations between specific psychotic symptoms and specific childhood adversities are mediated by attachment styles: an analysis of the National Comorbidity Study. *Psychiatry Research*, 217, 3, 202–209. Dozier, M., Stevenson, A.L., Lee, S.W. & Velligan, D.I. (1991). Attachment organisation and familial over-involvement for adults with serious psychopathological disorders. *Development and Psychopathology*, 3, 475–489.	P
	Depressive symptoms (non-clinical) & diagnosis of mood disorder	Ma, K. (2006). Attachment theory in adult psychiatry. [1] Conceptualisations, measurement, and clinical practice. *Advances in Psychiatric Treatment*, 12, 440–449.	M
	Diagnosis of obsessive compulsive disorder	Myhr, G., Sookman, D. & Pinard, G. (2004). Attachment security and parental bonding in adults with obsessive-compulsive disorder: a comparison with depressed out-patients and healthy controls. *Acta Psychiatrica Scandanavica*, 109, 447–456.	P
	Eating disorder	Ward, A.; Ramsay, R. & Turnbull, S. (2001). Attachment in anorexia nervosa: a transgenerational perspective. *British Journal of Medical Psychology*, 74, 497–505.	P
	Diagnosis of avoidant, depressive, paranoid or schizotypal personality disorder (associated with dismissing attachment)	Brennan, K. & Shaver, P. (1998). Attachment styles and personality disorders: their connections to each other and to parental divorce, parental death, and perceptions of parental care-giving. *Journal of Personality*, 66, 835–878.	M
	Diagnosis of dependent, histrionic or borderline personality disorder (associated with preoccupied attachment)	Fossati, A., Feeney, J.A., Donati, D., Donini, M., Novella, L., Bagnato, M., Carretta, I., Leonardi, B., Mirabelli, S. & Maffei, C. (2003). Personality disorders and adult attachment dimensions in a mixed psychiatric sample: a multivariate study. *Journal of Nervous and Mental Disease*, 191, 1, 30–37. Nakash-Eisikovits, O., Dutra, L. & Westen, D. (2002). Relationship between attachment patterns and personality pathology in adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41, 1111–1123.	M

Appendix 2. Table of assessments relating to attachment

Assessment Name	Age group	Used for ID?	Standardised Training required?	Clinical/ Research use	Mode of assessment	Focus of assessment (see 3.7)
Strange Situation	Child	Yes	Yes	Research & clinical	Observation	Representation (A,B,C,D)
Adult Attachment Interview	Adult	No	Yes	Research & clinical	Interview	Representation (F, D, E, U)
Attachment Q-Sort	Child	Yes	No	Research & clinical	3rd party observer rating	Representation (secure – insecure)
Adult Attachment Projective Picture System (AAP)	Adults	Yes	Yes	Research & clinical	'Judge' coded	Representation (F, D, E, U)
Secure Base Safe Haven Observation List (SBSHO)	Child & young people	Yes	No	Research & clinical	3rd party observer rating	Behaviours (secure)
Manchester Attachment Scale – Third party measure31 (MAST)	Adults	Yes	No	Clinical & research	3rd party observer rating	Behaviours (secure)
Quality of Early Relationship Rating Scale (QuERRS)	Adults	Yes	No	Clinical & research	Clinician rated	Relationship (A,B,C,D)
Choice-description method	Adolescents & adults	Yes	No	Clinical & research	Self-report	Style
The Disturbances of Attachment Interview (DAI)	Children	Yes	No	Clinical	3rd party interview	Disorder
Clinical Observation of Attachment (COA)	Children	Yes	No	Clinical & research	Observation	Disorder

Appendix 3. Further features of available attachment assessments

i) Secure Base Safe Haven Observation List (SBSHO). This list contains 20 items on a 7-point Likert scale and is intended for children with moderate to severe intellectual disabilities. The SBSHO is based on the Attachment Q-Sort which is a well-validated instrument for assessing attachment quality[81]. Although based on direct observation methodology, the SBSHO is based on third party judgements of attachment behaviours. Internal consistency has been reported as high, inter-rater agreement to be moderate (r=0.60) and concurrent validity was established against the Attachment Q-Sort.

ii) Manchester Attachment Scale – Third party measure (MAST). The MAST contains 16 items each consisting of a 4-point Likert scale, that a staff member or family carer will make ratings against judgements of attachment behaviour that they have observed in their caring role as with the SBSHO. The MAST was developed in work with adults, is internally consistent, and seems to be able to demonstrate a relationship between psychological and behavioural difficulties. Inter-rater reliability has not yet been reported.

iii) Quality of Early Relationship Rating Scale (QuERRS). Also for adults, the QuERRS is a 20-item rating scale to aid clinicians undertaking psychological therapies with persons who have mild to moderate ID, and who can refer to their family of origin and current relationships. The QuERRS asks the clinician to consider factor scores and then, if preferred, to consider the dominant category of attachment apparent in the therapeutic conversation. It appears to have acceptable inter-rater reliability and internal consistency[82], and may be able to predict if short or long-term psychotherapy is required if a psychodynamic approach is taken[83]. A Factor Analytic study[84] supports a four-factor solution with 16 items loading on (1) poor recollection versus realistic coherence, (2) unacceptability versus acceptability of the predictive value of attachments, (3) continued resentment of parents versus serenity towards difficulties, and (4) ongoing hypersensitivity to threat.

iv) Adult Attachment Projective Picture System (AAP). A trained and certified practitioner identifies the interpersonal expectations of the person from their response to a series of line drawings, achieving a detailed picture of their attachment

81 Van IJzendoorn, M.H., Vereijken, C.M.J.L., Bakermans-Kranenburg, M.J. & Riksen-Walraven, J.M. (2004). Assessing attachment security with the attachment Q sort: meta-analytic evidence for the validity of the observer AQS. *Child Development* 75, 1188–1213.

82 Skelly, A. & Reay, R. (2013). Quality of Early Relationships Rating Scale (QUERRS): A screening tool to aid psychotherapy assessment in people with mild to moderate learning disabilities. *Clinical Psychology and People with Learning Disabilities*, 11,1-2, 33–44.

83 Skelly, A. & Burman, H. (2015). Forty-four worthwhile interventions: Clinician-rated attachment style and outcome of psychodynamic psychotherapy for people with intellectual disabilities. *Bulletin of the Faculty for People with Intellectual Disabilities*, *13*(1), 20–29.

84 Skelly, A. & Harvey, H. (2017). Attachment representations in psychological therapy of people with Intellectual Disabilities: A preliminary factor analytic study of the Quality of Early Relationships Rating Scale (QuERRS). *The Bulletin of the Faculty for People with Intellectual Disabilities*, April.

representations with the confidence of a 'developmental' and diagnostic model rather than a hypothesis based on indirect ratings. A series of case studies demonstrating clinical utility in adults with mild to moderate ID has been reported[85]. The AAP requires considerable training in order to code transcripts reliably, and it is perhaps the most rigorous method available to be evidenced with adults with ID. Inter-rater reliability, test-retest reliability, and freedom from the effects of verbal intelligence or social desirability are described for mainstream use[86], along with excellent concurrent validity with the AAI. Recent work suggests that the AAP is especially useful in identifying a process of pathological mourning in adults presenting with psychological distress to clinical services[87].

v) The Clinical Observation of Attachment[88] (COA) is a structured observational assessment tool similar to the strange situation which places the child in anxiety provoking situations aimed to activate their attachment system. The child's attachment behaviours are rated, looking for the following: showing affection to the caregiver, seeking comfort, reliance on the caregiver for help, cooperation, exploratory behaviour, controlling behaviour, reunion responses, and response to strangers. Although developed as a measure for typically developing children, the assessment has been used successfully with children with ID. This approach can be used to guide observations and may be adapted for adults with ID by clinicians who have experience in working within an attachment informed framework.

vi) Choice-description method. This method involved participants choosing between self-descriptions of attachment style in romantic and friendship relations and adults[89] and also adolescents[90]. Issues have been raised in relation to the evidence produced by this method in terms of the ability to determine between-group effects with small sample sizes. We do not have reason to be confident that the attachment behaviour of the person would correspond to their choice of description. In addition, persons with dismissing (avoidant) categorisation may deny attachment problems because they psychologically avoid the salience of attachment difficulties to any behavioural or emotional symptoms they may have.

vii) Screening of Attachment Disorders. The Society explicitly encourages the use of psychological formulation as the end point of assessment for clinical psychologists, which may include diagnosis that has acceptable reliability and validity[91] but should

85 Gallichan, D. & George, C. (2014). Assessing attachment status in adults with intellectual disabilities: the potential of the Adult Attachment Projective Picture System. *Advances in Mental Health and Intellectual Disabilities*, 8, 103–119.

86 George, C. & West, M. (2011). The Adult Attachment Projective Picture System: Integrating Attachment into Clinical Assessment. *Journal of Personality Assessment*, 93, 5, 407–416.

87 Gallichan, C.J. & George, C. (2016). Attachment trauma and pathological mourning in adults with intellectual disabilities. In Fletcher, H.K., Flood, A. & Hare, D.J. (eds) *Attachment in Intellectual and Developmental Disability: A Clinician's Guide to Practice and Research.* New York: Wiley.

88 Boris, N.W., Fueyo, M. & Zeanah, C.H. (2007). The clinical assessment of attachment in children under five. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36, 2, 291–293.

89 Larson, F., Alim N. & Tsakanikos E. (2011). Attachment style and mental health in adults with intellectual disability: self reports and reports by carers. *Advances in Mental Health and Intellectual Disabilities* 5, 15–23.

90 Weiss J., MacMullin J., Waechter R. & Wekerle C. (2011) Child maltreatment, adolescent attachment style, and dating violence: considerations in youths with borderline-to-mild intellectual disability. *International Journal of Mental Health and Addiction* 9, 555–576.

91 Division of Clinical Psychology, British Psychological Society. (2011). *Good Practice Guidelines on the Use of Psychological Formulation.* Leicester, UK: BPS publications.

not be confused with psychiatric formulation which is centrally based on the diagnosis made in each case. Diagnosis is, therefore, something that psychologists may consider as neither necessary nor sufficient to determine that attachment is a central or important factor in their clinical formulation.

viii) The Disturbances of Attachment Interview (DAI)[92] is a 12-item semi-structured interview for caregivers, which was originally designed to screen for potential 'inhibition' (potential inhibited/emotionally withdrawn attachment disorder) and 'disinhibition' (potential disinhibited social engagement disorder). A study of 20 children with ID has demonstrated high inter-rater reliability, with inhibition associated to a history of multiple placements, and disinhibition associated with a history of poor parenting using negative emotional communication[93] . These findings suggest that the measure captures disturbance in attachment that is a result of negative experiences and finding those children whose circumstances may be significantly improved by intervention.

ix) Assessment (and treatment) of Reactive Attachment Disorder (RAD) in children was the subject of a detailed set of practice guidelines in the USA in 2005[94]. This is a specific method of assessment based on rigorous examination of the research evidence and is interesting because the structured or semi-structured observations with attachment figures and unfamiliar persons (analogous to the SSP), with variations in stress are recommended. In addition, an attachment history should be taken from the parents. Psychologists in adult ID services may be involved in cases where RAD was diagnosed in childhood. However, there is no adult assessment procedure available, and there is no evidence base for its use in children with ID, where behavioural phenotypes for some conditions and the person's cognitive functioning could potentially confound the findings.

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92 Gleason M.M., Fox N.A., Drury S., Smyke A., Egger H.L., Nelson C.A., Gregas M.C. & Zeanah C.H. (2011). Validity of evidence-derived criteria for reactive attachment disorder: Indiscriminately social/disinhibited and emotionally withdrawn/inhibited types. *Journal of the American Academy of Child and Adolescent Psychiatry*, 50, 216–231.

93 Giltaij H.P., Schuengel C. & Sterkenburg P.S. (2012) Disordered social behaviour in children with (mild) intellectual disability: Diagnostic distinctions between autism and disordered attachment. *Journal of Intellectual Disability Research*, 56, 680–680.

94 American Academy of Child and Adolescent Psychiatry. (2005). Practice parameter for the assessment and treatment of children and adolescents with reactive attachment disorder of infancy and early childhood. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44, 1206–1219.

Appendix 4. Self-assessment tool

Whilst there is still a limited evidence base to guide good practice in attachment and ID, this self-assessment tool has been developed based on the recommendations made in the NICE Guidelines *Children's attachment: attachment in children and young people who are adopted from care, in care or at high risk of going into care*[95] as the contents were felt to have good face validity for adults with ID. Whilst the tool is intended to help services **identify good practice** in working in an attachment-informed way it is not meant to be either prescriptive or limiting to services.

There are 7 proposed 'standards' included and blank templates to enable services to add to and develop their own 'standards' in addition to these. Services are encouraged to share additional standards with the working group who developed these guidelines so that these can be incorporated into future guidelines and standards as a continual work in progress.

As mentioned previously, it is important for clinicians to have a good understanding of attachment theory and the evidence base when using the self-assessment tool. Further research is needed to establish the validity of the 7 proposed standards within the tool for people with ID.

Standard 1 – Care co-ordination and stability	**Action to be taken**	**By whom?**	**Date to be completed/ reviewed**
Ensure that the health, education and social care processes and structures surrounding people with attachment difficulties are stable and consistent. This should include checking that for each individual service user the following are in place: • a care management system to coordinate care and treatment; • collaborative decision-making among all health, education and social care professionals, the individual if possible and their parents and carers; • the same key worker, social worker or personal adviser or care coordinator throughout periods of instability e.g. change of placement, loss or bereavement.			

95 NICE, (2015). *Children's Attachment: Attachment in children and young people who are adopted from care, in care or at high risk of going into care.* London: National Collaborating Centre for Mental Health.

Standard 2 – Identification of attachment difficulties	Action to be taken	By whom?	Date to be completed/ reviewed
Health and social care provider organisations should train key workers, social care workers and workers involved with adults with attachment difficulties in: • recognising attachment difficulties and parental/carer sensitivity; • recognising and assessing multiple socioeconomic factors that together are associated with an increased risk of attachment difficulties in the general population; • recognising and assessing other difficulties, including coexisting mental health problems and the consequences of maltreatment, including trauma; • knowing when and how to refer for appropriate interventions for attachment difficulties. Health and social care professionals should routinely ask questions relevant to attachment history and the individual's relationships with significant others during their initial assessments.			

Standard 3 – Training and support for carers supporting people with attachment difficulties	Action to be taken	By whom?	Date to be completed/ reviewed
Health and social care providers should: • Assess the need for comprehensive education and training for potential carers to prepare them for the challenges involved in supporting adults with attachment difficulties and the likely impact on them and their wider systems of support. • Provide on-going support and advice, either by telephone or in person, and proactively monitor difficulties in placements to identify opportunities to provide additional support, if there are significant attachment difficulties or if disruption to the placement is likely.			

Standard 4 – Care plans	Action to be taken	By whom?	Date to be completed/ reviewed
Health and social care providers should maintain an up-to-date care plan detailing: • How the adult will be supported with their attachment needs. • Who the key person will be who can advocate for the adult and to whom the adult can go for support. • If there is need for a safe space in which the person with attachment difficulties can go in times of emotional distress (with a plan as to how they will be supported at such times).			

Standard 5 – Interventions for adults in supported living/residential care	Action to be taken	By whom?	Date to be completed/ reviewed
Professionals with expertise in attachment difficulties should: • Work with the supported living/ residential staff group and identify any key attachment figures to work specifically with the person with attachment difficulties. • Offer parental sensitivity and behaviour training adapted for professional carers in supported living/residential care. • Ensure parental sensitivity and behaviour training for professional carers: – first consists of a single session with the carers followed by at least 5 (and up to 15) weekly or fortnightly carer–adult sessions (lasting 60 minutes) over 6 months – is delivered by a trained health or social care professional – includes: coaching the residential carers in behavioural management , reinforcing sensitive responsiveness, ways to improve caring quality – Includes homework to practise applying new skills.			

Standard 6 – Intensive support for placements at risk of breakdown	Action to be taken	By whom?	Date to be completed/ reviewed
Health and social care professionals arrange for additional support and resources (such as mentoring or day visits with a social worker or health professional) to adults and/or their carers: • at the first sign of serious difficulties in the placement, or; • if there have been frequent changes of placement, or; • if there is more than one adult with attachment difficulties in the placement.			

Standard 7 – Placement breakdown – supporting relationships to continue	Action to be taken	By whom?	Date to be completed/ reviewed
If a placement breaks down, aim to maintain the relationship between the adult and carers whenever possible and if it is in the best interests of the adult with attachment difficulties.			

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Division of Clinical Psychology

Faculty for People with Intellectual Disabilities

Positive Behaviour Support (PBS)

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Committee and Working Group Position Statement

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1. Summary

As a result of the broad range of needs that can arise in people with intellectual disability, there is a greater risk of them engaging in behaviours that may be viewed as challenging as a means of meeting their unmet needs and expressing their distress. Positive Behaviour Support (PBS) is currently considered to be the best practice approach to supporting individuals with intellectual disabilities who present with complex and challenging behaviour. PBS provides a person-centred and values-based, multi-component framework for assessing and understanding challenging behaviour using functional assessment. This leads to a formulation-based support plan that can draw upon a broad range of theoretically informed interventions, focusing on developing the quality of life of individuals; and reducing levels of challenging behaviour and the use of restrictive practices.

This position statement details our rationale as to why clinical psychologists are best placed to lead in the implementation, delivery, and associated training needs required within organisations, to support the implementation of PBS. Clinical psychologists' core skills in assessment, formulation, intervention, evaluation, and experience of training in a range of theoretical models and approaches are essential to the successful implementation of PBS. The context of PBS, the role of clinical psychology and recommendations for the development and delivery of PBS are outlined below in terms current national drivers for change in the England and the rest of the UK.

Whilst this guidance has been developed by the committee and working group of the Faculty for People with Intellectual Disabilities it is acknowledged that PBS is not just the work of clinical psychologists working with adults with intellectual disabilities. It is inherent with the practice of PBS that a broad range of professionals are required to support the implementation of PBS that truly meets the needs of those with challenging behaviour. Furthermore, it is acknowledged that the use of PBS is not limited to people with intellectual disabilities. However, the scope of this particular guidance is limited to clinical psychologists working in the field of intellectual disabilities.

2. Context

Challenging behaviour is described as behaviour that puts the individual or others at risk and/or could lead to the limitation of an individual's access to their community. There are many personal and environmental factors that can impact on behaviour. These include pain, physical health issues, communication difficulties, and environmental factors. In addition, the evidence base indicates that challenging behaviour and mental health difficulties can co-occur and be expressed as challenging behaviour. Understanding why an individual's behaviour is challenging requires those leading the assessment, formulation and intervention process to draw on a multi-theoretical knowledge base and associated skills. Clinical psychologists have key clinical, training and governance skills to equip them to lead and promote change, both at an individual, organisational and strategic level.

Individuals with intellectual disabilities and challenging behaviour are known to be at risk of exclusion, abuse and restrictive practices. A number of inquiries have highlighted both the urgent need to improve care provision and commissioning of services for individuals with intellectual disabilities and the challenges to implementing and sustaining change. These have included Winterbourne View (2012a), Cornwall (2006), Sutton and Merton (2007) inquiries into institutional abuse in services for people with intellectual disabilities. Most recently Stopping Over Medication of People with Learning Disabilities (STOMPwLD) (NHS England, 2016) renews the commitment to reducing the use of medication prescribed with the aim of reducing challenging behaviour and acknowledges the prioritisation of psychological or other interventions.

This position statement is in line with strategy, recommendations, progress reports and training programmes across all the UK nations which highlight the need to support people with intellectual disabilities, and those who support them, by delivering person-centred values-based approaches including PBS[1]. Developments are underpinned by the drive to reduce restrictive practices and improve on a systems-wide level, the lives of people with intellectual disabilities.

[1] DoH, Winterbourne View Concordat, 2012b; DoH, Transforming Care, 2012c, 2015; Service Model for Commissioners of Health and Social Care Services, 2015; Positive and Proactive Care, 2014; Positive and Proactive Workforce, 2014; Transforming care for people in Wales with learning disability and challenging behaviour: The five top priorities, 2013; Scottish Government, Keys to Life, 2013; PBS Competence Framework, 2015; Out of Sight, 2012. Mansell Reports,1993; 2007; Winterbourne View: Time for Change 2014; Key Messages about PBS 2017.

3. What we know

PBS is a human rights and person-centred based approach reflecting each person's individuality. It aims to promote quality of life, enhance community presence, increase independent living skills and places an emphasis on respect for the person being supported. It focuses on promoting proactive interventions to meet the individual's need and the avoidance of reactive/restrictive interventions, seeing these as the last resort option. Central to PBS is the assessment and formulation of the important function of behaviours that challenge within the individual's social and physical environment. The resulting PBS support plan is multi-component and draws on a range of psychological theories, models and approaches to promote an enhanced quality of life for the individual, ensuring that their needs are met and that there is a reduction in the likelihood of challenging behaviour. It focuses on ecological and antecedent interventions, and the development of skills to reduce the need for behaviours that challenge. Many interventions, including a range of psychological approaches, may be incorporated in the PBS plan.

The NICE guidance (2015) relating to individuals with learning disabilities and challenging behaviour, highlights the evidence base for core components of PBS. These are as follows:

- Functional assessment of behaviour;
- Personalised intervention, based in behavioural principles;
- Psychological interventions indicated before antipsychotic medication;
- Restrictive interventions are used as the last resort;
- Training for staff providing direct support in proactive interventions, in addition to high quality on-going supervision; and
- The use of routine outcome measures and periodic monitoring.

4. Why clinical psychologists are key in the implementation of PBS

Clinical psychologists have completed training to Doctoral level (DClinPsy) which at a minimum ensures they are competent in (a) the administration of psychometric assessments and the use and selection of outcome measures; (b) applying at least two major psychological theories and a range of models within these; (c) selecting and engaging in appropriate interventions, providing consultation and supervision, and working at the organisational level in the implementation of national policy.

This constellation of competencies and skills are ***essential*** *to the successful implementation of PBS,* to lead teams that provide PBS, and to take the lead in ensuring the governance of service delivery and positive outcomes. More specifically, the skills and competencies held by clinical psychologists that relate to the successful implementation of PBS are outlined below:

- Knowledge and skills ranging from biopsychosocial models and theory, (including relevant behavioural theory) to social policy.
- Commitment to delivering and supporting choice and control, respect and rights for people with intellectual disabilities, ensuring a human rights based approach underpins service delivery, both in specialist and mainstream settings.
- Knowledge of intellectual disabilities and behavioural phenotypes.
- A high level of applied behavioural analysis (ABA) training and delivery of specialist psychological assessments including neuropsychological testing, when indicated.
- An understanding and working knowledge of multiple theoretical perspectives informing the assessment and development of multi-component, theoretically based and formulation driven PBS plans. Facilitating understanding of the function of behaviour in the context of multi-agency systems and providing knowledge of a range of interventions in line with national guidance aimed at promoting the reduction in physical and chemical restraint.
- The provision of psychological therapies where indicated, as part of a broader PBS plan including trauma-based work, relational, systemic factors and difficulties with attachments.
- Clinical leadership competencies. This includes skills to understand, challenge and facilitate changes at a systemic level, in addition to facilitating and working with teams where case complexity requires innovative approaches to the implementation of PBS, both at an individual and service level.
- Knowledge and experience of working at an individual, group and organisational level in supporting the coproduction of PBS plans and their implementation involving all key stakeholders.
- Consideration of environmental change and adaptation. Contributing to the developments in planning and commissioning of placements and wider care packages and the development of housing strategies for people with behaviour that challenges, to ensure that people live and lead fulfilling lives, wherever possible, in the community.

- Competence in the selection of outcome measures and their adaptation to the client group and/or context where appropriate.
- Skills in identifying the need for, and providing training, consultation, supervision, and a reflective space to staff teams who support people with behaviour that challenges.
- Training and understanding in the legislation and practice relating to mental capacity, mental health and restrictive practices.
- Ensuring that PBS is delivered appropriately, that risk is assessed and positive risk taking is promoted.
- Skills to oversee the development and governance of PBS care pathways and processes and translate the evidence base into service descriptions and contribute to on-going research in relation to PBS.

5. Recommendations

Clinical psychologists have the training, skills and competencies to provide leadership in the implementation and development of PBS. They are well placed to ensure that training, research and governance systems are in place to establish PBS within current values, care and culture of services, and in turn, promote best practice improvements in the support and intervention for individuals with challenging behaviour. It is, therefore, recommended that clinical psychologists working in the field of intellectual disabilities should, as part of their role, endeavour to take on leadership roles and develop the clinical skills of services in the use of PBS.

It is recommended that the Faculty of People with Intellectual Disabilities has an on-going role in supporting the PBS agenda nationally through contributing to the development of policy and its translation into implementation. In addition, to ensure that clinical psychologists working in the field have the knowledge and skills to implement the recommendations outlined above, it is further recommended that the Faculty of People with Intellectual Disabilities provides relevant continuing professional development (CPD) events for its members and works closely with clinical psychology doctorate courses to develop teaching and competencies in the use of PBS during training. Whilst these recommendations apply specifically to clinical psychologists working with people with intellectual disabilities who present with challenging behaviour, it is important to note that this is an issue for all clinical psychologists. The Faculty will, therefore, continue, as part of these recommendations, to support other streams of work in relation to training and broadening the scope of clinical and other applied psychologists in their use of PBS.

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hcpc health & care professions council

Standards of proficiency

Speech and language therapists

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Foreword

We are pleased to present the Health and Care Professions Council's standards of proficiency for speech and language therapists.

We first published standards of proficiency for speech and language therapists when our Register opened in July 2003. We published revised standards in 2007. We review the standards regularly to look at how they are working and to check whether they continue to reflect current practice in the professions we regulate.

These new revised standards are a result of our most recent review of the standards of proficiency. As a result of the first stage of the review, and the results of a public consultation, we have revised our generic standards which apply to all the professions we regulate. The revised standards are now based around 15 generic statements. This new structure means that we can retain the standards which are shared across all the professions we regulate, whilst allowing us more flexibility in describing the detailed standards which are specific to individual professions.

The profession-specific standards for speech and language therapists included in this document were developed through the input of the relevant professional bodies and the views of all stakeholders during a further public consultation. The review process and consultation produced valuable feedback and we are grateful to all those who gave their time to help us in shaping the new standards.

We have made a small number of changes to the standards overall, mainly to reflect developments in education and practice, to clarify our intentions and to correct any errors or omissions. We have also made some minor changes to the introduction, in particular to explain the language we use in the standards.

We are confident that the standards are fit for purpose and reflect safe and effective professional practice in speech and language therapy.

These standards are effective from Monday 6 January 2014.

2 Standards of proficiency – Speech and language therapists

Introduction

This document sets out the standards of proficiency. These standards set out safe and effective practice in the professions we regulate. They are the threshold standards we consider necessary to protect members of the public. They set out what a student must know, understand and be able to do by the time they have completed their training, so that they are able to apply to register with us. Once on our Register you must meet those standards of proficiency which relate to the areas in which you work.

We also expect you to keep to our standards of conduct, performance and ethics and standards for continuing professional development. We publish these in separate documents, which you can find on our website.

The standards of proficiency in this document include both generic elements, which apply to all our registrants, and profession-specific elements which are relevant to registrants belonging to one of the professions we currently regulate. The generic standards are written in **bold**, and the profession-specific standards are written in plain text.

We have numbered the standards so that you can refer to them more easily. The standards are not hierarchical and are all equally important for practice.

A note about our expectations of you

You must meet all the standards of proficiency to register with us and meet the standards relevant to your scope of practice to stay registered with us.

It is important that you read and understand this document. If your practice is called into question we will consider these standards (and our standards of conduct, performance and ethics) in deciding what action, if any, we need to take.

The standards set out in this document complement information and guidance issued by other organisations, such as your professional body or your employer. We recognise the valuable role played by professional bodies in providing guidance and advice about good practice which can help you to meet the standards in this document.

Your scope of practice

Your scope of practice is the area or areas of your profession in which you have the knowledge, skills and experience to practise lawfully, safely and effectively, in a way that meets our standards and does not pose any danger to the public or to yourself.

We recognise that a registrant's scope of practice will change over time and that the practice of experienced registrants often becomes more focused and specialised than that of newly registered colleagues. This might be because of specialisation in a certain area or with a particular client group, or a movement into roles in management, education or research. Every time you renew your registration, you will be asked to sign a declaration that you continue to meet the standards of proficiency that apply to your scope of practice.

Your particular scope of practice may mean that you are unable to continue to demonstrate that you meet all of the standards that apply for the whole of your profession. As long as you make sure that you are practising safely and effectively within your given scope of practice and do not practise in the areas where you are not proficient to do so, this will not be a problem. If you want to move outside of your scope of practice, you should be certain that you are capable of working lawfully, safely and effectively. This means that you need to exercise personal judgement by undertaking any necessary training or gaining experience, before moving into a new area of practice.

Meeting the standards

It is important that you meet our standards and are able to practise lawfully, safely and effectively. However, we do not dictate how you should meet our standards. There is normally more than one way in which each standard can be met and the way in which you meet our standards might change over time because of improvements in technology or changes in your practice.

We often receive questions from registrants who are concerned that something they have been asked to do, a policy, or the way in which they work might mean they cannot meet our standards. They are often worried that this might have an effect on their registration.

As an autonomous professional, you need to make informed, reasoned decisions about your practice to ensure that you meet the standards that apply to you. This includes seeking advice and support from education providers, employers, colleagues, professional bodies, unions and others to ensure that the wellbeing of service users is safeguarded at all times. So long as you do this and can justify your decisions if asked to, it is very unlikely that you will not meet our standards.

Language

We recognise that our registrants work in a range of different settings, which include direct practice, management, education, research and roles in industry. We recognise that the use of terminology can be an emotive issue.

Our registrants work with very different people and use different terms to describe the groups that use, or are affected by, their services. Some of our registrants work with patients, others with clients and others with service users. The terms that you use will depend on how and where you work. We have used terms in these standards which we believe best reflect the groups that you work with.

In the standards of proficiency, we use phrases such as ‘understand’, ‘know’, and ‘be able to’. This is so the standards remain applicable to current registrants in maintaining their fitness to practise, as well as prospective registrants who have not yet started practising and are applying for registration for the first time.

These standards may change in the future

We have produced these standards after speaking to our stakeholders and holding a formal public consultation.

We will continue to listen to our stakeholders and will keep our standards under continual review. Therefore, we may make further changes in the future to take into account changes in practice.

We will always publicise any changes to the standards that we make by, for instance, publishing notices on our website and informing professional bodies.

Standards of proficiency

Registrant speech and language therapists must:

1 be able to practise safely and effectively within their scope of practice

1.1 know the limits of their practice and when to seek advice or refer to another professional

1.2 recognise the need to manage their own workload and resources effectively and be able to practise accordingly

2 be able to practise within the legal and ethical boundaries of their profession

2.1 understand the need to act in the best interests of service users at all times

2.2 understand what is required of them by the Health and Care Professions Council

2.3 understand the need to respect and uphold the rights, dignity, values, and autonomy of service users including their role in the diagnostic and therapeutic process and in maintaining health and wellbeing

2.4 recognise that relationships with service users should be based on mutual respect and trust, and be able to maintain high standards of care even in situations of personal incompatibility

2.5 know about current legislation applicable to the work of their profession

2.6 understand the importance of and be able to obtain informed consent

2.7 be able to exercise a professional duty of care

2.8 understand the ethical and legal implications of withholding and withdrawing feeding and nutrition

3 be able to maintain fitness to practise

3.1 understand the need to maintain high standards of personal and professional conduct

3.2 understand the importance of maintaining their own health

3.3 understand both the need to keep skills and knowledge up to date and the importance of career-long learning

4 be able to practise as an autonomous professional, exercising their own professional judgement

4.1 be able to assess a professional situation, determine the nature and severity of the problem and call upon the required knowledge and experience to deal with the problem

4.2 be able to make reasoned decisions to initiate, continue, modify or cease treatment or the use of techniques or procedures, and record the decisions and reasoning appropriately

4.3 be able to initiate resolution of problems and be able to exercise personal initiative

4.4 recognise that they are personally responsible for and must be able to justify their decisions

4.5 be able to make and receive appropriate referrals

4.6 understand the importance of participation in training, supervision and mentoring

5 be aware of the impact of culture, equality and diversity on practice

5.1 understand the requirement to adapt practice to meet the needs of different groups and individuals

5.2 recognise the possible contribution of social, psychological and medical factors to service users' communication difficulties and swallowing status

6 be able to practise in a non-discriminatory manner

7 understand the importance of and be able to maintain confidentiality

7.1 be aware of the limits of the concept of confidentiality

7.2 understand the principles of information governance and be aware of the safe and effective use of health and social care information

7.3 be able to recognise and respond appropriately to situations where it is necessary to share information to safeguard service users or the wider public

7.4 be aware that the concepts of confidentiality and informed consent extend to illustrative records such as photography, video and audio recordings

8 be able to communicate effectively

8.1 be able to demonstrate effective and appropriate verbal and non-verbal skills in communicating information, advice, instruction and professional opinion to service users, their relatives and carers, colleagues and others

8.2 be able to communicate in English to the standard equivalent to level 8 of the International English Language Testing System, with no element below 7.5[1]

This requirement is stricter for speech and language therapists than for all other HCPC-registered professions, as communication in English is a core professional skill (see standard 14.20)

8.3 understand how communication skills affect assessment of, and engagement with, service users and how the means of communication should be modified to address and take account of factors such as age, capacity, learning ability and physical ability

8.4 be able to select, move between and use appropriate forms of verbal and non-verbal communication with service users and others

[1] The International English Language Testing System (IELTS) tests competence in the English language. Applicants who have qualified outside of the UK and whose first language is not English must provide evidence that they have reached the necessary standard. Please visit our website for more information.

8.5 be aware of the characteristics and consequences of verbal and non-verbal communication and how this can be affected by factors such as age, culture, ethnicity, gender, socio-economic status and spiritual or religious beliefs

8.6 understand the need to provide service users or people acting on their behalf with the information necessary in accessible formats to enable them to make informed decisions

8.7 understand the need to assist the communication needs of service users such as through the use of an appropriate interpreter, wherever possible

8.8 recognise the need to use interpersonal skills to encourage the active participation of service users

9 be able to work appropriately with others

9.1 be able to work, where appropriate, in partnership with service users, their relatives and carers, other professionals, support staff and others

9.2 understand the need to build and sustain professional relationships as both an autonomous practitioner and collaboratively as a member of a team

9.3 understand the need to work in partnership with service users and carers in planning and evaluating diagnostics, treatments and interventions to meet their needs and goals

9.4 be able to contribute effectively to work undertaken as part of a multi-disciplinary team

9.5 understand the role of the speech and language therapist in taking the lead responsibility on speech and language communication and swallowing within a multi-professional forum

9.6 recognise that the need to work with others includes health, social care and educational professionals

9.7 recognise the importance of working in partnership with service users and their families

10 Standards of proficiency – Speech and language therapists

10 be able to maintain records appropriately

10.1 be able to keep accurate, comprehensive and comprehensible records in accordance with applicable legislation, protocols and guidelines

10.2 recognise the need to manage records and all other information in accordance with applicable legislation, protocols and guidelines

11 be able to reflect on and review practice

11.1 understand the value of reflection on practice and the need to record the outcome of such reflection

11.2 recognise the value of case conferences and other methods of review

12 be able to assure the quality of their practice

12.1 be able to engage in evidence-based practice, evaluate practice systematically and participate in audit procedures

12.2 be able to gather information, including qualitative and quantitative data, that helps to evaluate the responses of service users to their care

12.3 be aware of the role of audit and review in quality management, including quality control, quality assurance and the use of appropriate outcome measures

12.4 be able to maintain an effective audit trail and work towards continual improvement

12.5 be aware of, and be able to participate in, quality assurance programmes, where appropriate

12.6 be able to evaluate intervention plans using recognised outcome measures and revise the plans as necessary in conjunction with the service user

12.7 recognise the need to monitor and evaluate the quality of practice and the value of contributing to the generation of data for quality assurance and improvement programmes

13 understand the key concepts of the knowledge base relevant to their profession

13.1 understand the structure and function of the human body, together with knowledge of health, disease, impairment and dysfunction relevant to their profession

13.2 be aware of the principles and applications of scientific enquiry, including the evaluation of treatment efficacy and the research process

13.3 recognise the role of other professions in education, health and social care

13.4 understand the structure and function of education, health and social care services in the UK

13.5 understand the concept of leadership and its application to practice

13.6 understand the theoretical basis of, and the variety of approaches to, assessment and intervention

13.7 understand educational theory and practice and the relationship between language and literacy in relation to speech and language therapy

13.8 understand linguistics and phonetics, psycholinguistics, sociolinguistics and all levels of typical processing

13.9 understand biomedical and medical sciences as relevant to the development and maintenance of communication and swallowing

13.10 understand psychology as relevant to lifespan development and change, normal and impaired communication, and psychological and social wellbeing

13.11 understand sociology in relation to the practice of speech and language therapy, including its application to educational, health and workplace settings and within multi-cultural societies

13.12 understand therapeutic contexts, models and processes, relevant to the practice of speech and language therapy

13.13 understand developmental and acquired impairments of speech, language, communication and swallowing

14 be able to draw on appropriate knowledge and skills to inform practice

14.1 be able to change their practice as needed to take account of new developments or changing contexts

14.2 be able to conduct appropriate diagnostic or monitoring procedures, treatment, therapy or other actions safely and effectively

14.3 be able to formulate specific and appropriate management plans including the setting of timescales

14.4 be able to gather appropriate information

14.5 be able to select and use appropriate assessment techniques

14.6 be able to undertake and record a thorough, sensitive and detailed assessment, using appropriate techniques and equipment

14.7 be able to administer, record, score and interpret a range of published and self-generated assessment tools to describe and analyse service users' abilities and needs using, where appropriate, phonetic transcription, linguistic analysis, instrumental analysis and psycholinguistic assessment

14.8 be able to undertake or arrange investigations as appropriate

14.9 be able to analyse and critically evaluate the information collected

14.10 be able to demonstrate a logical and systematic approach to problem solving

14.11 be able to use research, reasoning and problem solving skills to determine appropriate actions

14.12 recognise the value of research to the critical evaluation of practice

14.13 be aware of a range of research methodologies

14.14 be able to evaluate research and other evidence to inform their own practice

14.15 be able to use information and communication technologies appropriate to their practice

14.16 be able to apply knowledge of communication impairment, linguistics, phonetics, psychology and biomedical sciences to the identification, assessment and differential diagnosis of a range of communication and swallowing impairments

14.17 understand health education and how it relates to communication and swallowing

14.18 be able to recognise the influence of situational contexts on communicative functioning and swallowing status

14.19 be able to evaluate the effects of communication difficulties and swallowing status on the psychosocial wellbeing of service users, their families and carers

14.20 as a core professional skill for speech and language therapists, be able to communicate in English to the standard equivalent to level 8 of the International English Language Testing System, with no element below 7.5

14.21 be able to use knowledge of speech and language therapy to assess and work with people with the following impairments:

- acquired speech and language impairments
- developmental or acquired cognitive impairments
- developmental speech and language impairments
- fluency impairments
- swallowing impairments
- voice impairments

15 understand the need to establish and maintain a safe practice environment

15.1 understand the need to maintain the safety of both service users and those involved in their care

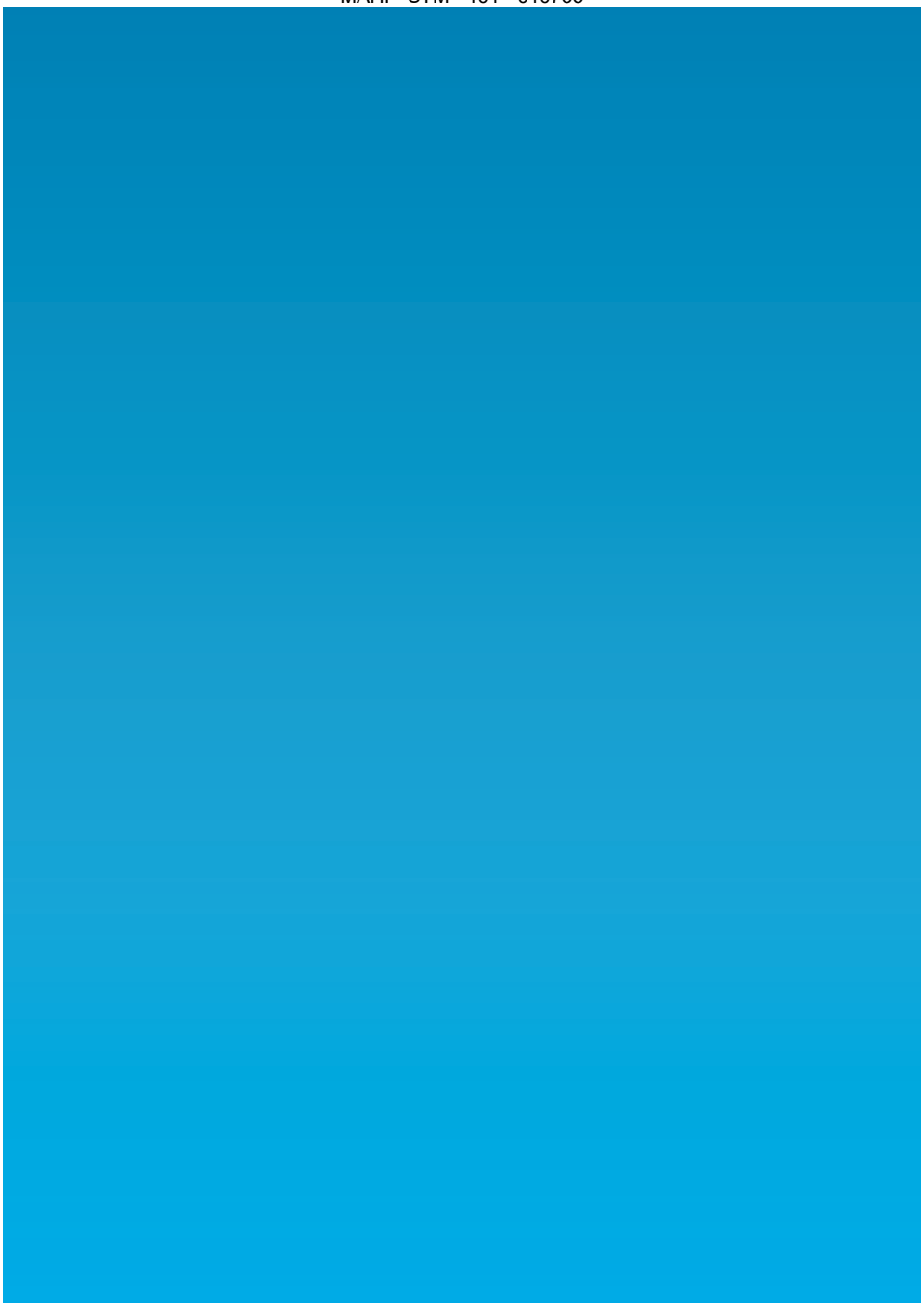
15.2 be aware of applicable health and safety legislation, and any relevant safety policies and procedures in force at the workplace, such as incident reporting, and be able to act in accordance with these

15.3 be able to work safely, including being able to select appropriate hazard control and risk management, reduction or elimination techniques in a safe manner in accordance with health and safety legislation

15.4 be able to select appropriate personal protective equipment and use it correctly

15.5 be able to establish safe environments for practice, which minimise risks to service users, those treating them and others, including the use of hazard control and particularly infection control

Notes



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ROYAL COLLEGE OF SPEECH & LANGUAGE THERAPISTS

Position Paper

Speech and Language Therapy Provision for Adults with Learning Disabilities

March 2003

EXECUTIVE SUMMARY

The development of the position paper

This position paper on speech and language therapy services for people with learning disabilities has grown out of the work of the Clinical Guidelines Project. Therapists involved in the Project identified a need for a statement on good practice which went beyond the prescribed remit of clinical guidelines, which could review conceptual frameworks alongside current research evidence and begin to develop professional consensus for therapists working in this field. This was seen as crucial for a specialism that was relatively new, and rapidly expanding.

The document is intended to complement the recommendations given in the Clinical Guidelines. The clinical guidelines document focuses on the principles, and the evidence base that supports those principles. This document provides a detailed account of the principles and processes surrounding good practice. It also discusses the wider policy and service delivery issues that therapists need to engage with if they are to work effectively in this field. The writing of the paper coincided with the publication of influential government directives on the future of services to people with learning disabilities (Department of Health 2001a; Scottish Executive 2000, National Assembly of Wales, 2001) and it is therefore aligned with these new directives.

The writing of the position paper

In 2001, therapists involved in the Guidelines Project recommended that RCSLT hold a national forum in order to ensure that therapists across the UK could contribute to the writing of this paper. The forum was held in July 2001, and was attended by a wide representation of practitioners from across the UK. (College has a list of all those who attended which could be added as an Appendix to the paper) The consensus views that emerged from this forum were then collated by a small working group and distributed for wider consultation. Further consultation was conducted across a variety of professional networks involving RCSLT advisers and special interest groups and encompassed therapists from all regions of the United Kingdom. A number of revisions to the paper were then undertaken before the final paper presented to the RCSLT for ratification.

The structure of the position paper

The paper uses a working model for the range of work undertaken by Speech and Language Therapists with adults with learning disabilities. This includes

Key Principles

1. Commitment to the promotion of independence, choice, inclusion and civil rights
2. Consideration of communication needs in the context of a social model of disability
3. Partnership with local policies, resources, and priorities
4. Value, respect and promotion of all modalities of communication
5. Maximising of service user involvement at all levels
6. Collaboration across agencies, professional groups and the lifespan of people with learning disabilities
7. Intervention linked to the life aims and identified priorities of individuals.
8. Reflection on values and belief systems.

Main Processes

All processes used can take place at one or more of person, environment or community level and include

1. Specialist clinical and therapeutic skills
    - Assessment and evaluation
    - Working holistically
2. Facilitation of others
    - Accessible Information
    - Training and development
3. Service Development
    - Working with Speech and Language Therapy colleagues
    - Working with Learning disability services
    - Working with welfare and other services

Main conclusions

The specialism of adult learning disability has generated great innovation and creativity within the therapists who work in this field. This position paper is a reflection of that innovation and creativity. Used well, it should allow therapists to articulate the principles and processes that underpin their work. The principles outlined in this paper underpin processes that will continue to be diverse, reflecting local agendas, situations and contexts. It is vital that therapists continue to disseminate and share good practice so that speech and language therapy services across the United Kingdom can become ever more effective in their work with people with learning disabilities.

Working party membership

Sue Thurman
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ROYAL COLLEGE OF SPEECH & LANGUAGE THERAPISTS

Position Paper – 2003

Speech and Language Therapy Provision for Adults with Learning Disabilities

A. INTRODUCTION

1. Definitions

The term 'learning disability' can be defined in many different ways. Historically it has been defined within a biomedical paradigm. The World Health Organisation define it as "*a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence i.e., cognitive, language, motor and social abilities*" **(ICD–10,1992, p.369)**.

More recently, however, definitions have been based upon functional descriptors and the level of support required by the individual **(Department of Health, 1992, 2001a)**. Increasingly, the broader definition of "disability" is being set within a socio–political framework **(Finkelstein, 1980; Oliver, 1980, 1996; ICIDH–2, 1999, Department of Health, 2001)**. The most recent directive from the World Health Organisation suggests that that there is a need to use a "diagnostic" framework *in conjunction* with one that provides a description of the consequences of the disability on everyday functioning **(ICIDH–2, 1999, p.8)**.

> *Learning disability includes the presence of:*
> - *A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with*
> - *A reduced ability to cope independently (impaired social functioning);*
>
> *which started before adulthood, with a lasting effect on development*
>
> **(Department of Health 2001a, page 14)**

It is difficult to be precise about the number of people with learning disabilities. Prevalence figures vary depending upon the definitions applied, the age of the population and level of severity of learning disability **(McLaren and Bryson, 1987; Farmer et al, 1991; Welsh Health Planning Forum, 1992)**. The Department of Health estimates that in England there are 210,000 children and adults with severe and profound disabilities and 1.2 million with

mild and moderate disability (**Department of Health, 2001a**). In Scotland there are thought to be 120,000 people with learning disabilities (**Scottish Executive, 2000**).

2. Important influences

The writing of this paper coincided with the publication of influential government directives on the future of services to people with learning disabilities (**Department of Health 2001a; Scottish Executive 2000, National Assembly of Wales, 2001**). This position paper is therefore aligned with these new directives.

3. Reaching consensus

Within speech and language therapy, working with adults with learning disabilities is a relatively new specialism (**Pearson, 1995**). There is a correspondingly small amount of experimental research evidence in the field. This is in part due to the small numbers of speech and language therapists who work in this area (**Bailey and Cooper, 1997**). It is also due to the nature of the research undertaken by practitioners. Large-scale experimental designs have not been either favoured or feasible, and the research has tended to be small scale, and non experimental in design.

The literature on guideline development suggests that new specialisms such as this one need to begin the process of developing guidelines by

a) Using as broad an evidence base as is available (non experimental research, grey literature, reports and policy directives) and
b) Developing guidelines by consensus.

The process adopted by the RCSLT involved reviewing the literature in the prescribed way (**Taylor Goh and Brennan, 1999**), and, in addition, holding a national forum for therapists working in the field. The forum was attended by a wide representation of seventy practitioners from across the UK. Its aim was to review current research evidence and conceptual frameworks, and begin to develop professional consensus. The forum restricted itself to consideration of the communication needs of people with learning disabilities. The reader is referred to the RCSLT guidelines on dysphagia for this aspect of the role of the Speech and Language Therapist with people with learning disabilities. The consensus views that emerged from this process were collated by a small working group and distributed for wider consultation. This position paper is the end result of the consultation process. It is being used as the basis for the guidelines for working with adults with learning disabilities, which will follow the RCSLT agreed format for guidelines.

4. The structure of the position paper

There are many different ways of conceptualising the range of work undertaken by Speech and Language Therapists with adults with learning disabilities. For the purposes of this position paper, the working model includes

- **Principles** – the underlying basis of service delivery, reflecting philosophy, values and purpose
- **Processes** – the ways in which the principles are put into practice

B. PRINCIPLES

Eight key principles that underpin good practice have been devised by consensus for this guideline.

1. Speech and Language Therapy service delivery is committed to the promotion of independence, choice, inclusion and civil rights

'Valuing People' sets out four key principles that should underpin the delivery of all services; facilitating choice and independence, and promoting social inclusion and civil rights (**Department of Health, 2001a**). These principles are reflected in the guidance for all UK countries. They are essential if people with learning disabilities are to achieve equal status in society.

In order for individuals to exercise real **choice**, people with learning disabilities have to have the means and opportunities to do so. Providing opportunities for understanding and expressing choices at realistic and achievable levels for individuals, alongside appropriate advocacy services, should be fundamental to the planning and delivering of services. Speech and Language Therapists have a key role in determining an individual's capacity to make choices, since language is fundamental to the process of representing and internalising available and possible choices and communicating them to others in the environment.

In this context, **social inclusion** means enabling people with learning disabilities to *'...make use of mainstream services and to be fully included in the community*" (**Department of Health 2001a, p24**). Without shared communication, there is automatic exclusion and isolation. Progress towards real social inclusion is only possible through effective communication. Speech and Language Therapists have a key role to play in this through commitment to social inclusion policy at a local level (**Bunning and Grove, 2002**). This includes influencing policy and practice by raising awareness of the fundamental role of communication, ensuring access to community and mainstream services through developing consistent and readily available training and resources in partnership with users, carers and other professionals.

In order to achieve **independence** in their daily lives, people with learning disabilities need to be given appropriate support. A difficulty with, or lack of, communication, significantly impairs the ability to achieve independence. For Speech and Language Therapists this impacts on their work in direct clinical work, consultancy and training. Many people with learning disabilities will require support with their understanding and expression throughout their lives. The individual can be empowered to achieve the greatest possible autonomy through developing shared communication using whatever means are appropriate.

Legislative changes have been put in place to uphold the **civil rights** of citizens (**the Human Rights Act, 1998; the Disability Discrimination Act, 1995; the Race Relations Act, 1976; the Race Relations (Amendment Act) 2000; the Sex Discrimination Act 1975; Mental Health Act, 1983, Youth and Criminal Justice Evidence Act, 1999**). People with learning disabilities have the same civil rights as those of all other members of society. People with learning disabilities have the right to..."education, to grow up to vote, to marry, to have a family, and to express their opinions, with help and support where necessary" (**Department of Health, 2001a, p23**). Speech and Language Therapists have an important role in assisting

people with learning disabilities to both fulfil their right to shared communication (**ASHA 1992**) and also to understand and exercise all the rights enshrined in this legislation.

2. Speech and Language Therapy service delivery considers communication needs in the context of a social model of disability

Speech and Language Therapists, in common with other health and social care professionals, are increasingly adopting approaches based on the consequences of disability, commonly referred to as the social model of disability (**Finkelstein, 1980; Oliver, 1996; Shakespeare and Watson, 1997**). This shift away from a predominantly 'medical' model of disability is a pre-requisite to work in this area. Communication skills are of crucial importance to the quality of life of individuals with learning disabilities (**van der Gaag, 1998; Jones, 2000**). Maximising the effectiveness of communication for the individual, those in their immediate environment and their local communities are all valid target areas for Speech and Language Therapists to focus their work. It is also important that Speech and Language Therapists recognise the broader societal issues for people with learning disabilities. If Speech and Language Therapists are to be actively involved in maximising the communication skills of people with learning disabilities, then they must deliver their services within this context, working closely with the service user and other health and social care professionals. Various authors have commented that communication difficulties amongst adults with learning disabilities remain a significant barrier to social integration (**Calculator and Bedrosian, 1988**), involvement in decision-making (**Carnaby, 1997**), and involvement in research (**Booth and Booth, 1996**). Difficulties with communicating have also been found to give rise to frustration, anxiety, withdrawal (**Leudar and Fraser, 1985**), anger (**Gilmour and Miller, 1996**) and behaviours that challenge services (**Carr and Durand, 1985; Mansell, 1993; Thurman, 1997; Bradshaw, 1998, 2000**).

3. The practical delivery of Speech and Language Therapy services to adults with learning disabilities is in line and in partnership with local policies, resources, and priorities

'Valuing People' (**Department of Health 2001a**) requires that all organisations working with people with learning disabilities develop communication policies and produce and disseminate information in 'accessible formats.' 'The Same as You' recommends that '*SAIF (Scottish Accessible Information Forum) should consult local authorities, health boards and users and carers on how best to provide joint, one-stop, free and accessible information'* (**Scottish Executive, 2000**). For communication policies to be effective, there is a need to support individual communication needs whilst also enabling those in the individual's environment(s) and community to have access to information, training and continuing support. Considerable commitment, energy and resource is required from organisations if this process is to result in materials that are effectively accessible to people with learning disabilities. In 'Valuing People' (**Department of Health 2001a**) and in 'Nothing About Us, Without Us' (**Department of Health, 2000**), organisations are encouraged to involve people with learning disabilities in constructing the policies relevant to them. People with learning disabilities have been largely excluded from this process (**Coldham and Marler, 2002**) or involved as a tokenistic 'add-on' (**Simons, 1999**). The Speech and Language Therapist is able to facilitate the communication skills of people with learning disabilities to enable them to participate in developing services appropriate to them. This discipline possesses the skills required to: (a) advise organisations on how to develop real participation; (b) enable the

person with learning disability to understand key topics at issue and (c) facilitate the expression of their views and wishes.

Current literature suggests that there is considerable variation in the provision of Speech and Language Therapy services across the UK (**Bailey and Cooper, 1997; Money, 2000; van der Gaag et al, 1999; Dobson and Worrall; 2001**). It is therefore important that priorities for the delivery of Speech and Language Therapy are devised in conjunction with local policies, resources, priorities, and if appropriate, eligibility criteria. This also recognises that the responsibility for promoting effective communication does not lie with Speech and Language Therapists alone; communication is a shared responsibility amongst all of those who live or work with people with learning disabilities.

4. All modalities of communication are valued, respected and promoted by Speech and Language Therapists

The Foundation for People with Learning Disabilities (2000) notes that

- Between 50% and 90% of people with learning disabilities have communication difficulties, whilst about 80% of those with severe learning disabilities do not to acquire effective speech.
- About 60% of people with learning disabilities overall have some skills in symbolic communication, such as speech, signs or picture symbols.
- About 20% have no verbal communication skills but do demonstrate intentional communication whilst up to 20% have no intentional communication skills.

It is therefore important to promote access to all modalities of communication if people are to access their rights to communication (**ASHA, 1992**) The aim of this is to enable the individual to "*...communicate freely in all ordinary communication situations and a range of less ordinary ones.*" (**Martinsen and von Tetzchner, 1996**) The use of 'Total' or 'Inclusive' Communication is increasingly recognised as best practice and effective use of Speech and Language Therapy resources (**Jones 2000, Bradshaw 2000a**). The use and definition of the terms 'Total' or 'Inclusive' communication varies. For the purpose of this document they are used to describe an approach that seeks to create a supportive and effective communication environment, using every available means of communication to understand and be understood.

People with profound and multiple learning disabilities require very specific assessment and support if they are to enjoy the right to communicate (**Bradley, 1998**). Up to 20% of the total learning disabled population will not have achieved intentional communication and are frequently labelled 'non-communicators'. **Bradley (1998)** points out that any useful definition of communication must encompass both intentional and pre-intentional elements. Successful communicative environments for the person with profound learning disabilities will involve 'communication partnerships' (**Bartlett and Bunning, 1997; Bradshaw, 2001a**) and explore means of promoting positive interactions (**Fogel, 1993**).

5. Speech and Language Service delivery maximises service user involvement at all levels

Person Centred Planning (**O'Brien and Lovett, 1992**) is a widely used framework for implementing the principles of normalisation or social role valorisation (**Wolfensberger**

1983) in health and social care contexts. Recent government directives recommend that all services for people with learning disabilities make use of this framework (**Department of Health, 2001a,g; Scottish Executive, 2000; National Assembly of Wales, 2001**). This includes Speech and Language Therapists working with this service user group.

The Department of Health (**2001 b-f; www.doh.gov.uk/consent**) and the Scottish Executive (**2001**) have issued guidance to health professionals on obtaining consent from service users in relation to treatment. The literature to date has reported that service user involvement in all levels of decision making, including consent, can frequently be tokenistic (**Greasley, 1995; Gudjonsson and Clare, 1995; Heal and Seigelman, 1995; Lloyd et al, 1996; Grove et al 1999**). In the case of someone with profound and complex learning disabilities, this involvement is often likely to be non-existent (**Foundation for People with Learning Disabilities, 2000**). Very specific intervention is required over a considerable period if there is to be real consultation regarding real and meaningful choices for people with profound and complex disabilities (**Sanderson, 1998; Bradshaw, 2001a; Smith, 2001**) Examples of such interventions include Communication Passports, (**FPLD, 2000**) and Circles of Support (**Wertheimer, 1995**).

Service users should be meaningfully involved in decisions about their therapy. Speech and Language Therapists should therefore work to equip others with the specialist communication skills needed to maximise the participation of people with learning disabilities in consent, advocacy, planning and delivery of their services.

6. A collaborative approach to service delivery across agencies, professional groups and also across the lifespan of the people with learning disabilities is essential

Speech and Language Therapists are the professionals who have traditionally provided the expertise in the area of communication difficulty. They have the skills and knowledge necessary for assessing, enabling and supporting adults with learning disabilities and those who work with them in order to maximize communication. However they achieve this through training, consultancy and other inter-disciplinary work with health and social care professionals and carers, alongside their specific therapeutic approaches (**Money 1997, Purcell et al, 1999; 2000**). Purcell et al point out that some research has shown that carers often underestimate hearing difficulties and overestimate language skills of people with learning disabilities (**Purcell et al, 1999; Bradshaw 2001b**). Carers may have a tendency to be over reliant on verbal, as opposed to non-verbal, exchanges, as well as using complex language, questions and directions (**Jones, 2001**).

Speech and Language Therapists need to promote the communication needs of the individual as part of an overall planning process. Speech and Language Therapists should ensure that individuals are supported by appropriate, relevant and consistent means of communication. It is important to achieve a consistent and coherent approach to communication throughout a person's life. It is essential therefore that services co-operate in ensuring consistency in all environments and through all transitions across services. This requires a high level of inter-agency working and partnership with children and young peoples' services in which Speech and Language Therapists need to be proactive. It is also vital to take full account of the cultural and linguistic needs of individuals and communities in delivering services (**RCSLT 1998, Mir et al 2001**)

7. All Speech and Language Therapy intervention is linked to the life aims of the individual in agreement with identified priorities

In line with Person Centred Planning (**Department of Health 2001a; Scottish Executive, 2000; National Assembly of Wales, 2001**) the extent to which the intervention has changed the individual's ability to understand and be understood needs to be reviewed in the light of its impact in enabling the person with learning disabilities to fulfil life aims. These may include

- Making choices (**Grove et al, 1999**)
- Self advocating and acting independently (**Goodley, 2000; Atkinson, 1999; Evans, 1999**)
- Creating and sustaining relationships (**McCarthy, 1999; McCarthy and Thompson, 1995; Brown, 1994; Lesseliers, 1999**).
- Understanding and being understood by others (**Bradshaw 2001b; Bartlett and Bunning 1997**)
- Accessing and giving relevant information **(Chapman and Forshaw 2002)**
- Participating in preferred activities (**Money and Collins 1999**)
- Coping with change and making transitions (**Hollins and Sireling, 1994; Maddon, 1991**)
- Experience positive communication (**Couchman 1995**)
- Give consent (**Arscott et al, 1999, DoH, 2001**)
- Participating in decision-making about housing (**Simons, 1999, 1995**)
- Engage in supported employment (**Beyer, 1995**)

8. Speech and Language Therapists reflect on their own values and belief systems in the context of their work

Much has been written about the impact of personal values and belief systems on the delivery of welfare services (**Balint, 1957, Illich, 1977; O'Brien and Lovett, 1992**). Policy makers and service managers are becoming increasingly aware of the need for staff to reflect on their personal values and beliefs on an ongoing basis, as well as having adequate supervision and support (**Williamson 2001**). Speech and Language Therapists can engage in 'values' awareness initiatives (for example, diversity awareness, disability awareness training), which aim to promote self-reflection and critical analysis of this aspect of their professional practice. This form of self-reflection can be a valuable part of continuing professional development and the promotion of good practice.

C. PROCESS

In order for Speech and Language Therapists to maximise the communication skills of people with learning disabilities, they must deliver their services within a broad context and work closely with other health and social care professionals. A variety of approaches are likely to be used, and these may include one or more of the following

- Assessment and evaluation
- Producing a formulation based on this evaluation and devising a plan with clear objectives
- Advice/consultation/ co-working with others
- Training/ teaching/ transmitting information

- Coaching/ enabling/ resourcing
- Change management
- Service development

These approaches can be used at different levels, and are not mutually exclusive

- **Person** – where the focus of intervention will be the individual's communication
- **Environment** – where there are changes in people, processes or settings within a person's (or group of people's) environment, which will increase the individual's inclusion in social networks. This will often be needed to support work at the 'person' level
- **Community** – where the communication for adults with learning disabilities is enhanced through influencing attitudes, cultures or practices within the local community

Whatever approach is used, and at whatever level, it must always be person centred, and must involve working in partnership with others. The Speech and Language Therapist has to combine assessment, planning, facilitating, training and service development, in order to maximise the person with learning disabilities' effective communication (**Money, 1997; Jones, 2000, Bradshaw, 1998; Thurman, 1997; Purcell et. al, 2000**).

It is not appropriate to provide a complete list of all the possible variations and combinations of approaches that are offered by Speech and Language Therapists. The scope of each local speech and language therapy service will vary, reflecting staffing, funding, expertise and the local agendas of both statutory and non-statutory agencies. Therefore whilst some services may use a broad range of the processes described in this paper, others may only use a few and deliver a more specific or targeted service. However for the purpose of this paper the following are examples of processes in use across the UK. They have been categorised as under three broad headings

- Specialist clinical and therapeutic skills
- Facilitation of others
- Service development

1. Specialist clinical and therapeutic skills

This is achieved through direct application of the Speech and Language Therapist specialist skills

1.1 Assessment and evaluation: Any communication assessment carried out by a qualified Speech and Language Therapist takes into account the individual's life experience, their communication ability and understanding, their environmental constraints and opportunities and the potential for change. The Speech and Language Therapist explores communication within the context of different life opportunities with people with learning disabilities and their carers

The Speech and Language Therapist will carry out a communication assessment based on sound clinical judgement using a range of formal and informal methods. This may be at the three levels

- **Person** - their understanding, communication modalities and ability, personal circumstances, sensory and other health needs
- **Environment** - barriers and opportunities in the communication environment including carer understanding of the person, communication modalities used, communication partner interaction styles
- **Community** – accessibility of information, social networks and neighbourhood links.

Wherever it is appropriate to carry out an individualised communication assessment, Speech and Language Therapists should use an assessment suited to the communication needs and interests of the individual. This should be carried out in collaboration with carers. There is evidence that different methods of assessment generate different but complementary descriptions of an individual's communicative abilities (**Dormandy and van der Gaag, 1989**), and therefore one approach, e.g. assessment of functional communication, should not be used to the exclusion of all others.

The assessment must focus on assessing carers' skills (**van der Gaag, 1989a; Granlund et. al, 1992; Money 1997; Hodgkinson, 1998**) and assessing environmental influences on communication (van der Gaag, 1989b). There is evidence to suggest that the physical properties of the environment (**von Tetzchner et al 1996**), the relationship between the speakers (**Jackson 1993**) and the opportunities for communication and the demands placed upon individuals to communicate (**van der Gaag 1989b**) all influence the process of communication. It is essential that an individual's communication needs are clearly identified and shared with all those involved.

1.2. Working holistically: The Speech and Language Therapist provides appropriate based intervention following the findings of the assessment with reference to the multi-disciplinary team.

This may include

- Working in partnership with the individual to develop communication skills / strategies he/she desires or needs. This may include developing conversation skills, extending sign vocabulary or enhancing fluency.
- Working in partnership with SLT colleagues who have specialist expertise (e.g. dementia, dysphonia, stroke etc).
- Sharing knowledge /skills with people within the individual's environment
- Using a Person Centred Planning approach
- Introducing specific communication skills to facilitate health issues, including mental health issues, health promotion, hospital admission, experience of chronic pain, or palliative care.
- Implementing specific programmes as appropriate e.g. Individualised Sensory Environments (**Bunning 1998**), Intensive interaction (**Nind and Hewitt, 1996, Hewitt and Nind, 1998**), social use of language (**Rinaldi, 1992**), sensory processing approaches, (**Bhreathnach 1992, Mulcahy 1994, Chu and Green 1996**), social skills programmes, etc.
- As Health Facilitators, supporting people with learning disabilities in accessing primary health care.
- Assisting in Adult Protection inquiries and in providing appropriate preventative and therapeutic interventions

- Supporting other professionals and people with learning disabilities within the Criminal Justice system

2. Facilitation of others

This is achieved through advice and support or training and development.

2.1 Accessible Information: The Speech and Language Therapist acts as a specific resource for issues concerning communication, through involvement with health, education, private and voluntary sectors, the work place, housing, community facilities, and involvement with inter-agency initiatives. The purpose of this is to overcome communication barriers which impact on people' choices, social inclusion, civil rights or independence.

The Speech and Language Therapist should seek to facilitate and empower **Individuals and groups of individuals** with learning disability. The Speech and Language Therapist may maximise communication through advice, support and provision of resources. This could involve, for example

- Advising advocacy groups (**Goodley, 2000**)
- Providing informed expert professional opinion around issues such as consent or forensic or legal services. (**Hollins and Sireling 1994; Bull, 1995; Cambridge, 2001**).
- Assisting in the protection of vulnerable adults and young people, working with the multi-disciplinary team (**Brown & Turk, 1992; Quigley, 1999**)

The Speech and Language Therapist may advise and support others in developing appropriate communicative **environments** (**Bradshaw, 1998; Bartlett, 1997**). This could include

- The production and dissemination of accessible information, advice or appropriate resources
- Analysing existing communication strategies within specific environments and modifying and developing these
- Advice or curriculum development for colleagues e.g. working in further education, contributing to undergraduate and postgraduate training
- The development of appropriate health promotion materials or providing access to health education.

The Speech and Language Therapist may raise awareness of the communication needs of people with learning disability within the wider **community**. This may involve

- Contributing to induction programmes of health and other professionals
- Responding to requests for support from other community services such as banks, libraries, hospitals, leisure facilities (**Matthews and Dean, 1999).**

2.2 Training and development: Speech and Language Therapists play a pivotal role in communication training for other professionals and carers

Speech and Language Therapy training for other professionals, families and friends needs to be delivered systematically in order to be effective (**Money 1997, van der Gaag 1998, Purcell 2000**). Speech and Language Therapists may be involved in teaching others to recognise the fundamentals of communication. Training may be delivered at an

- **Individual level** - focussed on an individual's communication, raising awareness and developing skills and strategies specifically tailored to the individual's need.
- **Environment level** - focussed on the communication of a person or people and their partners within a specific environment.
- **Community level** – focussed on raising awareness in the local community, improving social networks, improving access to community pursuits and making information accessible

The nature of training varies depending on context. Its objectives can be to

- Establish a basic common understanding of the communication process
- Discuss the nature of communication breakdown, its consequences for a person with a learning disability and the impact on communication partners
- Develop strategies and approaches such as Total Communication, Intensive Interaction
- Provide specific information, such as hearing loss, understanding, choices, abuse, challenging needs, autism
- Facilitate an opportunity for problem solving

Speech and Language Therapists can use education, training and development to meet identified communication needs as part of their intervention. This can

- Change behaviour
- Raise awareness
- Change attitudes
- Increase competence

It has been suggested that teaching can be an effective component of service delivery, provided it is flexible, small scale, facilitated by local Speech and Language Therapists, adapted to the needs of the individual staff, practical and straight forward and supported by management (**van der Gaag, 1998**). Formal 'one–off' staff training delivered without any follow-up rarely has any long-term effects on staff behaviour. (**Ziarnik and Bernstein, 1982; Cullen, 1988; Money, 1997**) The ultimate benefit of staff training procedures must be evidenced in positive changes in the lives of people with learning disabilities. (**Purcell et. al, 2000**). **van der Gaag (1998**) states that teaching is most effective when the techniques used include the ongoing use of feedback, both video, verbal and written; management support is secured; training is tailored as closely as possible to the individual staff; and training is practical and straight forward. **Purcell and colleagues (2000**) suggest that effective communication training has four main features.

- Firstly, it should take place in the work place and be based around situations and context within staff's daily work.

- Secondly, it should focus on those people with learning disabilities with whom staff frequently interact.
- Thirdly, a more experienced colleague, who has day-to-day knowledge of the individuals concerned and has the opportunity to work alongside staff, should guide training.
- Lastly, communication styles that facilitate people with learning disabilities' communication should be assessed, documented and evaluated and then shared with a wider staff group.

The new Learning Disability Awards Framework (LDAF) and Scottish Vocational Qualifications (SVQ) provide nationally recognised routes to qualification for care workers (**Department of Health, 2001a; SVQ, 2001**). Speech and Language Therapists should take into account local implementation of such initiatives through influencing local training policies and/or direct delivery of training.

3. Service Development

This may involve working with speech and language therapy colleagues, learning disability services or welfare and other services.

3.1 Working with Speech and Language Therapy colleagues: Speech and Language Therapists record and share their growing experience and knowledge base to achieve a high level of consensus

Speech and Language Therapy provision for adults with learning disabilities is a new and expanding area of professional practice. It is therefore essential to promote sharing of skills and experience and to minimise isolation of practitioners. It is recommended that *'good practice, ideas and innovations (which have been evaluated) are systematically disseminated within and outside the organisation'* (**Department of Health 1997**). One of the priorities for therapists working in this field is to generate evidence which can in time be used to guide policy and practice.

This can be done through a variety of methods

- Membership of relevant Specific Interest Groups.
- Publishing successful therapy initiatives in relevant journals.
- Presenting results of any initiatives at relevant conferences, workshops or seminars.
- Identifying specialist areas, eg dysphagia, mental health, challenging behaviour, autistic spectrum disorders, sensory impairment.
- Ongoing documentation of therapy objectives and outcomes.
- Undertaking and supporting research
- Reflective practice and ongoing clinical supervision
- Clinical governance initiatives (**NHS Executive, 1999**)

3.2 Working with Learning disability services: Speech and Language Therapists take a proactive role in highlighting the communication issues inherent in delivering high quality services

Speech and Language Therapists are expected to work as part of a multi-disciplinary team to provide people with learning disabilities with well-coordinated packages of care (**RCSLT, 1996**). Additionally as appropriate, Speech and Language Therapists may be involved in

- Advising Partnership Boards (**Department of Health, 2001a**) on policy issues where an understanding of the communication needs of people with learning disabilities is of central importance to effective implementation and creation of those policies. This is key to social inclusion.
- Advising provider agencies in developing protocols and procedures, local standards and service level agreements and inter agency partnerships arrangements. Service User involvement in planning, developing and evaluating services is central. The Speech and Language Therapist has expertise in the provision of training, advice and support to enable these organisations to develop protocols, procedures, guidelines which ensure that service users can express their views in a meaningful way and receive feedback in an appropriate form.
- Service Evaluation, which can be implemented through a variety of methods, including interviews, questionnaires and/or observational methods. (**Money and Collins, 1999**). For example, service evaluation by service users may allow individuals to express basic rights regarding who they want to live with, where they live, work and the type of professional service they receive. Speech and Language Therapists have specific skills and knowledge to identify meaningful levels of participation that enable persons with learning disability to express their opinions to the full extent of their ability (**Grove, et. al, 1999**).

3.3 Working with welfare and other services: In order to achieve an inclusive society all services in the wider community should meet the needs of people with learning disabilities. Speech and Language Therapists work with these services in order to achieve this in appropriate and sensitive ways

Other services where the Speech and Language Therapist can play a role include the criminal justice system, advocacy services, housing providers, leisure services and employment services (**Simons, 1999**). For example, Speech and Language Therapists may contribute to a greater understanding amongst criminal justice professionals of the communication difficulties of people with learning disability and how to respond appropriately to them. Speech and Language Therapists are appropriate professionals to train as intermediaries (**Home Office, 1998**). Contribution can be made to policies, procedures, training, PACE (**HMSO 1984**), and resources. The Speech and Language Therapist brings a unique perspective on the nature of the individual's communication needs and their impact on the psychosocial construction of criminal activity. Research shows the individuals with learning disability and communication difficulty are more likely to become involved with criminal justice both as alleged victims and perpetrators (**Hayes and Craddock, 1992, Hayes, 1998**).

The Speech and Language Therapy profession recognises that work opportunities, choice in housing options and how to spend leisure time are central components of quality of life. Therapists can bring specific expertise in enabling individuals with learning disability to make specific and informed choices regarding their everyday lives and experiences.

D. CONCLUSION

The emergence of this position paper has reflected the innovation and creativity that exists within this specialism. In the future, the document will be enhanced by further consultation and revision in the light of new evidence. Consultation with service users and other stakeholders, utilising appropriate and meaningful mechanisms, will be an important part of the continuing evolution of this work. (**Department of Health 2000**) The principles of our services as outlined in this paper, form the basis of the RCSLT Clinical Guidelines, and the processes will continue to be diverse, reflecting local agendas, situations and contexts. In time, we will gather more evidence through a variety of research initiatives including action research and other qualitative methodologies. It is important that therapists continue to disseminate and share good practise so that speech and language therapy services across the UK can become ever more effective in their work with people with learning disabilities.

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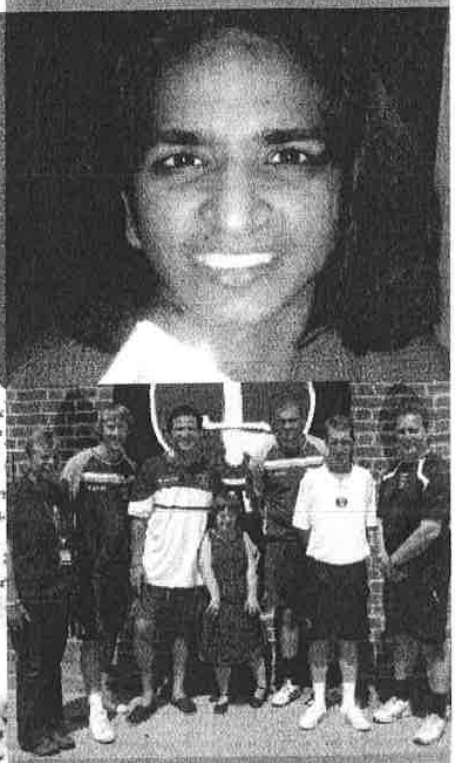
Adults with learning disabilities (ALD)

Position Paper

RCSLT

May 2010





ROYAL COLLEGE OF SPEECH & LANGUAGE THERAPISTS

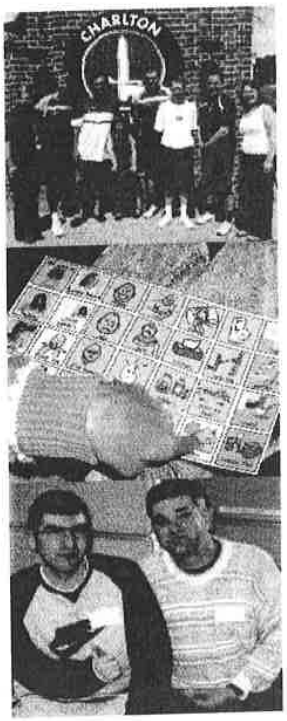
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ROYAL COLLEGE OF SPEECH & LANGUAGE THERAPISTS

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The paper was developed and written by the ALD Position Paper Steering Group, which comprised of Viki Baker, Louise Oldnall, Elenor Birkett, Geraldine McCluskey and Jo Morris.

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Executive summary

This document identifies the role of speech and language therapists (SLTs) in adult learning disability services across the UK. This information should support SLTs, speech and language therapy managers, speech and language therapy educators and other organisations that support people with learning disabilities in their role. This document aims to define the best practice for SLTs in learning disability services within the context of national policy frameworks. The paper has been written in consultation with the speech and language therapy workforce and other key stakeholders. It is recognised that any future development to this work should include more collaboration with service users and carers.

The ALD Position Paper defines the existing speech and language therapy workforce and reinforces some key messages for speech and language therapy educators in relation to preparing SLTs for working in ALD services.

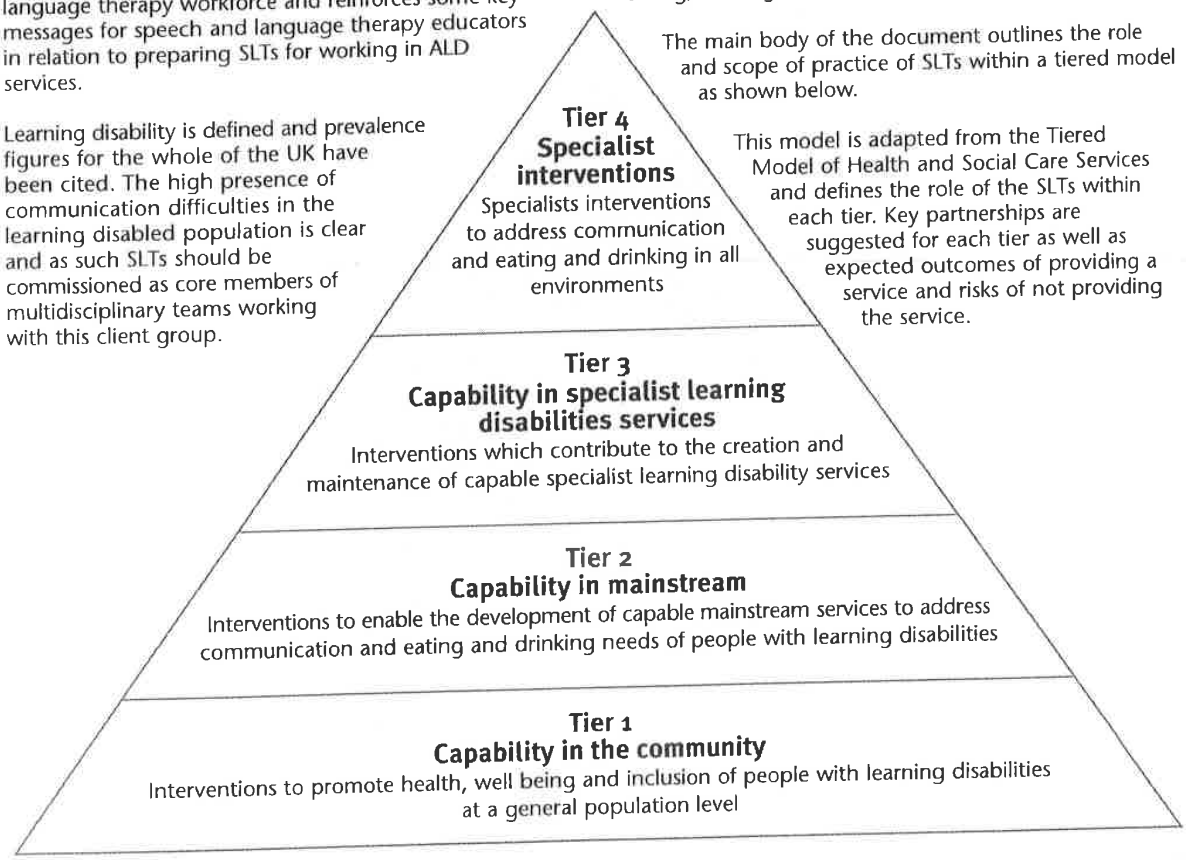
Learning disability is defined and prevalence figures for the whole of the UK have been cited. The high presence of communication difficulties in the learning disabled population is clear and as such SLTs should be commissioned as core members of multidisciplinary teams working with this client group.

Speech and language therapy services should work within and be defined by current policy frameworks and key policy drivers are given for each country it is envisaged that all SLTs will be familiar with these documents and so be able to translate national strategy and ideology into best practice.

The visions and values that should underpin every speech and language therapy service are discussed within the context of the social model of disability. Speech and language therapists should place the service user at the centre of their intervention and work in partnership with them and their significant others to address their communication barriers and/or eating/drinking difficulties.

The main body of the document outlines the role and scope of practice of SLTs within a tiered model as shown below.

This model is adapted from the Tiered Model of Health and Social Care Services and defines the role of the SLTs within each tier. Key partnerships are suggested for each tier as well as expected outcomes of providing a service and risks of not providing the service.



Throughout each tier there are examples of best practice that clearly show the role of an SLT. The key messages behind this model are:

- Speech and language therapy should work at all tiers. This will range from providing a service that promotes the health, well being and inclusion of people with learning disabilities through to direct specialist interventions that address a person's individual communication or eating and drinking needs.
- Speech and language therapists need to develop partnership working with others at each tier.
- Speech and language therapists should work within a person-centred framework.
- Local commissioning arrangements and service capacity will determine to what extent particular SLTs can work within the model. However, the model should be seen as a conceptual framework for good practice within speech and language therapy and can be used to support local service development and delivery.

The Position Paper addresses the role of the SLT in producing accessible information and emphasises the importance of this work being developed and carried forward in partnership with other agencies.

The importance of a competence-based workforce is identified. Speech and language therapists need to be open to workforce re-design and put the needs of the service user before professional boundaries. The speech and language therapy assistant practitioner should be seen as an integral member of the team and should support SLTs to provide a person-centred service.

This document recommends that the speech and language therapy workforce (through the national ALD leads network) address certain key points that have arisen during the development of the Paper. These workforce and performance issues will be relevant to all services and require consideration from the profession as a whole.

Full references are given and this document should be read in conjunction with other key documents produced by the Royal College of Speech and Language Therapists.

1. Introduction

The political and social climate for speech and language therapists (SLTs) working with people with a learning disability continues to change and develop at pace. Since the original Royal College of Speech and Language Therapists' (RCSLT) position paper, Speech and Language Therapy Provision for Adults with Learning Disabilities (2003) there has been significant change and growth within this area. For example, the Speech and language therapy profession within adult learning disability has seen a development of posts and clinical specialisms, the development of a progressive national network and considerable innovative practice across the UK.

The majority of SLTs are based in learning disability teams. These teams, however, are organised and structured differently across regions and countries of the UK. Some SLTs in England are seconded to, or employed by the local authority, some are employed by the independent and voluntary sector, while most remain directly employed by the NHS.

Whereas 10 years ago speech and language therapy work in adult learning disabilities could have been described as having a low profile within the profession, and often within multidisciplinary teams, now the picture is very different. Speech and language therapists are seen as a core profession working in adult learning disability services, and the profession itself is recognising that much work with adults with learning disabilities is cutting edge, characterised by progressive strategic thinking, partnership working, and embracing the social model of disability. The speech and language therapy profession needs to ensure there is a greater awareness of communication as a basic human right and that this should be recognised at a strategic level by commissioners. It is fundamental that people with learning disabilities themselves, alongside SLTs, lead the work and campaign for communication rights.

The authors of this document recognise people with a learning disability are themselves experts in communication due to their having first-hand experience of living with communication barriers. Perhaps it is a limitation of this paper that it has been written by professionals working in the field and national organisations that represent user groups with little user voice.

We would, however, both hope and envisage that future work stemming from this paper will be developed in partnership, where possible, with people with learning disabilities and their families as partners. It is this group that should be at the heart of speech and language therapy service planning and redesign.

2. Purpose and intention

What has become evident in the process of consultation with the profession for the purposes of writing this paper is the overwhelming passion, energy and commitment for people with learning disabilities to be included as valued members of society, and the core role SLTs have in enabling inclusion to happen.

This paper aims to offer guidance to SLTs and speech and language therapy managers in order to influence commissioning arrangements and higher education (for the purposes of speech and language therapy education and academic research). It is hoped the paper will also be useful for other organisations committed to supporting the rights of people with learning disabilities. It includes:

- Key strategic and policy drivers influencing practice.
- Values embedded within speech and language therapy practice.
- Role and scope of speech and language therapy practice.
- Advice on service models and structures.
- Evolving roles and workforce issues for the profession.
- Questions for future consideration and discussion.
- Key research and evidence base.

This paper should be used in conjunction with the following key publications produced by the RCSLT:

The Quality Self-Evaluation Tool (Q-SET) demonstrates how speech and language therapy services meet the need of service users. It provides evidence of the effectiveness of activities and this is useful in communicating the value of learning disability services to commissioners and helps to identify areas for improvement. It can also be used as a national benchmarking tool and it is recommended that all services complete Q-SET to develop a body of evidence to enable comparison.

The Resource Manual for Commissioning and Planning Services for SLCN (Speech, Language and Communications Needs) (RCSLT, 2009) supports RCSLT members to communicate more effectively with commissioners. It includes a synthesis of the evidence about speech, language and communication needs to inform commissioning based on systematic searching and expert review. The document includes:

- Incidence and prevalence figures.
- Range of interventions available.
- Effectiveness of interventions available.
- Relative cost effectiveness of those interventions (where evidence exists).
- A prioritisation process which manages health gain across the population as a whole.

3. Process for consensus and method of analysis

The process to gain consensus regarding the content of this position paper has been the following:

- Election of a steering group from within the national network. All members of the group have a considerable background in working with people with a learning disability and are all lead SLTs or senior speech and language therapy service managers in the UK.
- Holding a series of seven consultation events across the UK in London (two events), the south west of England, the north west of England, the Midlands, Scotland and Northern Ireland.
- Each of the events followed the same format, using discussion groups working to a service model (described later in the paper). Issues raised were discussed and debated where necessary and results collated by the steering group. All events have been led by members of the steering group to ensure consistency between them.
- In addition to these seven events, there has been a range of special interest group meetings and regional leads meetings that have also focused on the paper.
- The paper itself was produced in draft form and circulated broadly within the profession and, in its final draft to key stakeholders, for example, organisations representing service user groups. Consensus regarding its content and necessary changes was made using SurveyMonkey as a tool.
- Advisers have been invited to all consultation events, and their comments and recommendations included in redrafts.
- Comments from consultation have been analysed in depth and included or discussed in the re-write.



Linda Clark, a service user who is employed as a speech and language therapy assistant, provided signing training for Charlton Community Trust Football coaches

4. The speech and language therapy workforce

Speech and language therapy is a degree level entry profession and all practising SLTs are required to be registered with Health Professions Council (HPC). Membership of the RCSLT is recommended. The HPC and RCSLT have codes of practice, conduct and standards which govern speech and language therapy practice.

Speech and language therapists are the lead experts regarding communication and eating and drinking/dysphagia. The level of pre-registration education and later experience enables SLTs to lead on the assessment, differential diagnosis, intervention with and management of individuals with communication and eating and drinking difficulties/dysphagia. It is recognised that SLTs will liaise and work closely with other agencies and other professions.

Speech and language therapy assistants are integral members of the speech and language therapy team employed to act in a supporting role under the direction of a professionally qualified SLT. (Further guidance on the specialist ALD speech and language therapy workforce is discussed later in the document.)

4.1 Pre-registration education of student SLTs

The national ALD Network completed and circulated a set of recommended 'core messages' by consensus in 2007 for universities and colleges providing speech and language therapy education training, in relation to work in adult learning disability services. These are:

- Students will have knowledge of the values and philosophy of the Social Model of Disability.
- Students will understand the need for delivery of speech and language therapy, employing various models at the level of the individual, environment and population. This is now superseded by the Tiered Model of Health and Social Care services adapted for speech and language therapy ALD service delivery model (described later in the paper).
- Students will have knowledge of relevant government legislation and strategy relating to LD in that country.
- Students will have insight into the importance of training others as fundamental in underpinning speech and language therapy work.
- Students will have awareness of the variety of work within the area of ALD: forensic, dysphagia, profound and multiple learning disabilities, challenging behaviour, autistic spectrum disorder, mental health.

As each course is varied in terms of the time and teaching methods/placements and so on, this paper recommends local speech and language therapy teams in adult learning disability services form a close working relationship with their local university to ensure the messages above are included in the courses/education training in the most efficient way for that particular course.

It is important here to note that all students, regardless of future specialism, should have the above as a baseline of knowledge so that any SLTs can work more effectively with people with a learning disability.

5. Definitions

Learning disability

There are several ways in which the term 'learning disability' can be defined; however, for the purposes of this paper we are using the following:

Central UK Government and the regional and devolved governments within Valuing People 2001 (England), Equal Lives 2005 (Northern Ireland), Same as You 2000 (Scotland) and Fulfilling the Promises 2001 (Wales), give a definition which includes three elements all of which much be present:

- A significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence).
- A reduced ability to cope independently (impaired social functioning).
- These are in evidence before adulthood and have a lasting effect on development.

This paper in line with MENCAP and the World Health Organisation, amongst others, adopts the social model of disability as the overarching model.

The two key areas of assessment and intervention for SLTs are communication impairment and eating and drinking difficulties/dysphagia.

Communication difficulty

Up to 90% of people with learning disability have communication difficulties; with half having significant difficulties. Many people with profound and multiple learning disabilities have extremely limited communication ability which may be restricted to behaviours such as eye gaze and changes in facial expression. Whilst communication difficulties vary greatly from person to person, it is acknowledged that barriers to successful communication are often social ones, eg a focus on written information questionnaires to obtain people's views. Communication difficulties that people with learning disabilities may experience include:

- Understanding speech, writing and symbols, and interpreting environmental sounds.
- Having a sufficient vocabulary to express a range of needs, ideas or emotions.
- Being able to construct a sentence.
- Maintaining focus and concentration in order to communicate.
- Dysfluency, eg stammering.
- Being able to articulate clearly which may be due to related physical factors.
- Social skills, a lack of which may prevent positive interactions with people.

(From Working with adults with a learning disability, A Kelly, 2002)

Eating and drinking/dysphagia

In 2004, the National Patient Safety Agency (NPSA) identified dysphagia as one of the five key areas of risk for people with learning disabilities.

Dysphagia refers to difficulty in eating, drinking or swallowing. It can lead to malnutrition, dehydration, reduced quality of life and choking. Asphyxia and respiratory-related mortality are known to be disproportionately high in people with learning disabilities.

"Dysphagia can occur as a result of either a single medical problem, eg stroke, progressive neurological condition, or as a result of:

- Oropharyngeal structural problems.
- Motor processing difficulties.
- Central nervous system disorders.
- Pharyngo-oesophageal problems.
- Poor oral health.
- The psychological effects of institutionalisation.
- Mental health problems.
- The effects of medication."

(NPSA, Dysphagia (2008))

6. Prevalence

It is estimated in **England** that:

- 169,000 people aged 20 or over (0.46% of the adult population) are known users of learning disability services in England. Of these, 26,000 are aged 60 or over.
- There will be a sustained growth in the numbers of people with learning disabilities known to services over the next 10 to 20 years:
  - 11% over 2001-2011
  - 14% over 2001-2021
- The estimated number of people with learning disabilities in England will therefore also increase:
  - 15% over 2001-2011
  - 20% over 2001-2021
- In common with general life trends there will be marked increases in the numbers of people with learning disabilities known to specialist services aged 50+:
  - 28% over 2001-2011
  - 48% over 2001-2021
- More people with mild to moderate learning disabilities will become known to and start using services. Therefore, the total numbers of people using services is set to increase:
  - By more than 50% to 223,000 by 2018

(Healthcare Commission, 2007; DOH, 2009)

In **Scotland** it is estimated that:

- 20 people for every 1,000 have a mild or moderate learning disability.
- Three to four people for every 1,000 have a profound or multiple disability.
- Approx 120,000 people with learning disability in Scotland.
- These figures will grow by 1% per year.

(Same as You, 2000)

In **Wales** it is estimated that:

- There are 10,450 people with learning disabilities over the age of 16.
- 360-380 per 100 000 total population have severe learning disabilities.

(Statement on Policy and Practice for Adults with a Learning Disability, 2007)

In **Northern Ireland** it is estimated that:

- A combined prevalence of all people with learning disabilities has been reported as 9.7 people per 1,000 people in the population.
- There are an estimated 8,200 people aged 20+ who present with learning disabilities. This figure is derived from those known to services and there is likely to be an unrecognised population of people with mild learning disabilities of approximately 16,000 who are not known to services.
- It is predicted that these figures will grow by 1% per year. However, this may be slightly higher in NI due to demographic trends.

(Equal Lives, 2005)

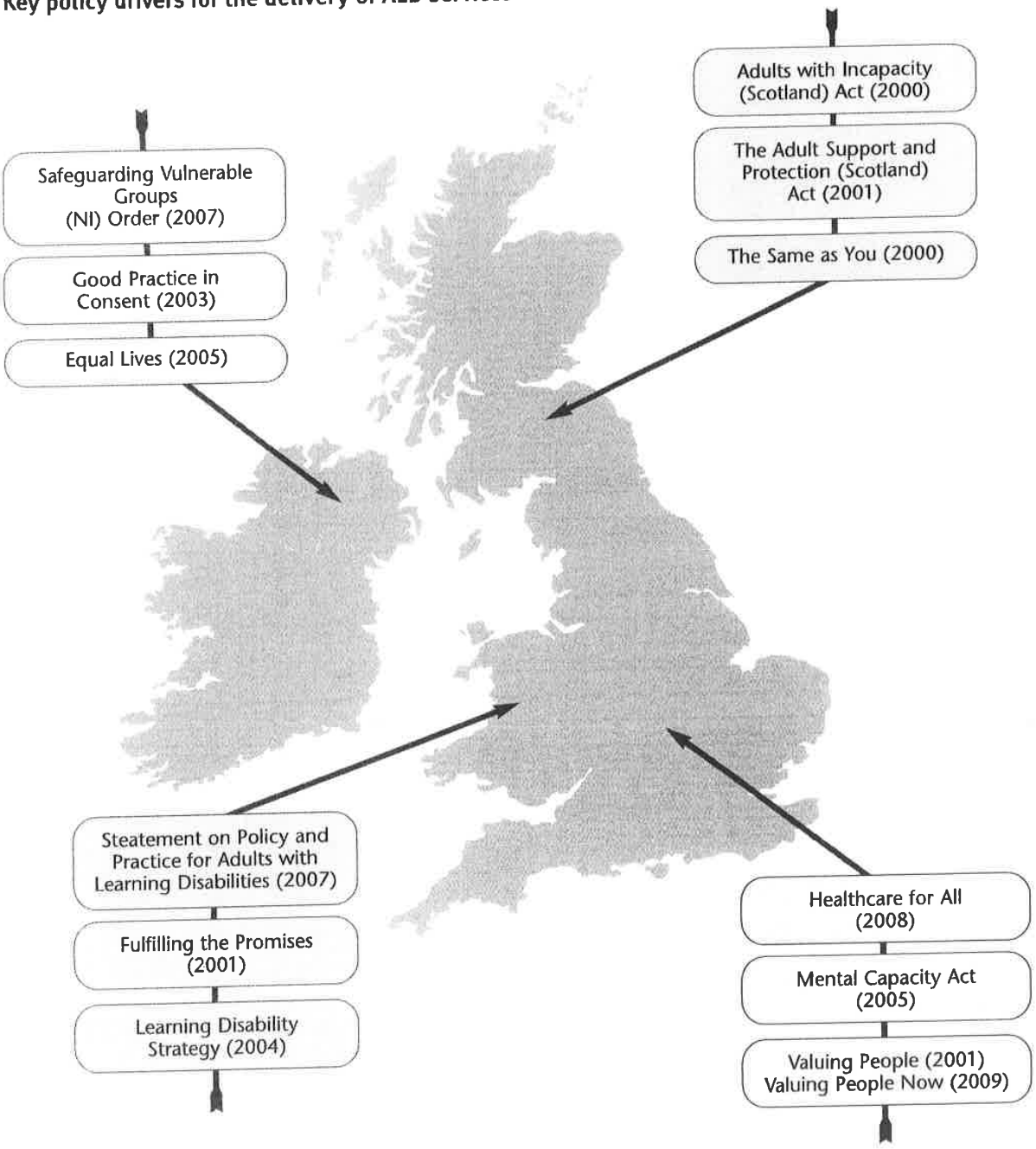
Enderby et al (2009) reported:

- 50%-90% of the learning disabled population have communication difficulties (Enderby and Davies, 1989: RCSLT.CQ3, 2006).
- 80% of people with severe learning disabilities do not acquire effective communication (RCSLT, CQ3, 2006).
- One third of all speech and language therapy services in the UK are directed at the learning disabled population (RCSLT, CQ3, 2006).
- 89% of people with learning difficulties need speech and language therapy intervention (Bradshaw, 2007).
- 45% of people with learning difficulties have serious communication problems (Bradshaw, 2007).
- Half of people with intellectual disability have significant communication problems and up to 80% have some communication problems (Scottish Government 2000).

There are no reliable figures on the prevalence of dysphagia in people with learning disabilities. Figures range from 36% based on general speech and language therapy caseloads to 73% based on inpatient populations (Leslie, Crawford and Wilkinson, 2008). What is accepted is that the ALD population has a higher incidence of health problems including dysphagia than the general population (RCSLT CQ3, 2006; Death by Indifference, 2007; Valuing People Now, 2009).

Chadwick et al 2003 (cited in RCSLT, CQ3 2006), found that 5.27% of all adults with learning disability were referred for advice regarding dysphagia.

Key policy drivers for the delivery of ALD services



For other infuential policies/reports see reference list.

7. Vision and values

People with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services (United Nations, 1994).

This statement has been selected as it encapsulates the vision and values of all UK regional and devolved governments' strategies

The **social model of disability** proposes that barriers and prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society. It recognises that while some people have physical, intellectual, or psychological differences from a statistical mean, which may sometimes be impairments, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are 'normal' (BILD, 2006).

The social model of disability "sees disability as created by social barriers rather than individual impairment" (Walmsley, 2001) p195.

The overall aim for SLTs is to work in the context of the social model of disability by:

- Enabling others to address the barriers to communication that adults with a learning disability experience.
- Maximising the opportunities for positive interactions, participation and choice for people with learning disabilities.
- Working as part of a multidisciplinary team to ensure that adults with learning disabilities can eat and drink as safely and enjoyably as possible.

The specific objectives of speech and language therapy interventions is to work in partnership with individuals with learning disabilities, their carers, other significant people and the wider community to enable people to:

- Understand and express the choices available to them
- Express their views.
- Access services.
- Be included and involved.
- Maintain health and well being.
- Develop personalised services.

These roles can be applied to any area of an individual's life. This may include, for example, health, education, leisure or employment. These will depend upon:

- The individual's needs.
- Local priorities.
- Circumstances influencing effectiveness of intervention.

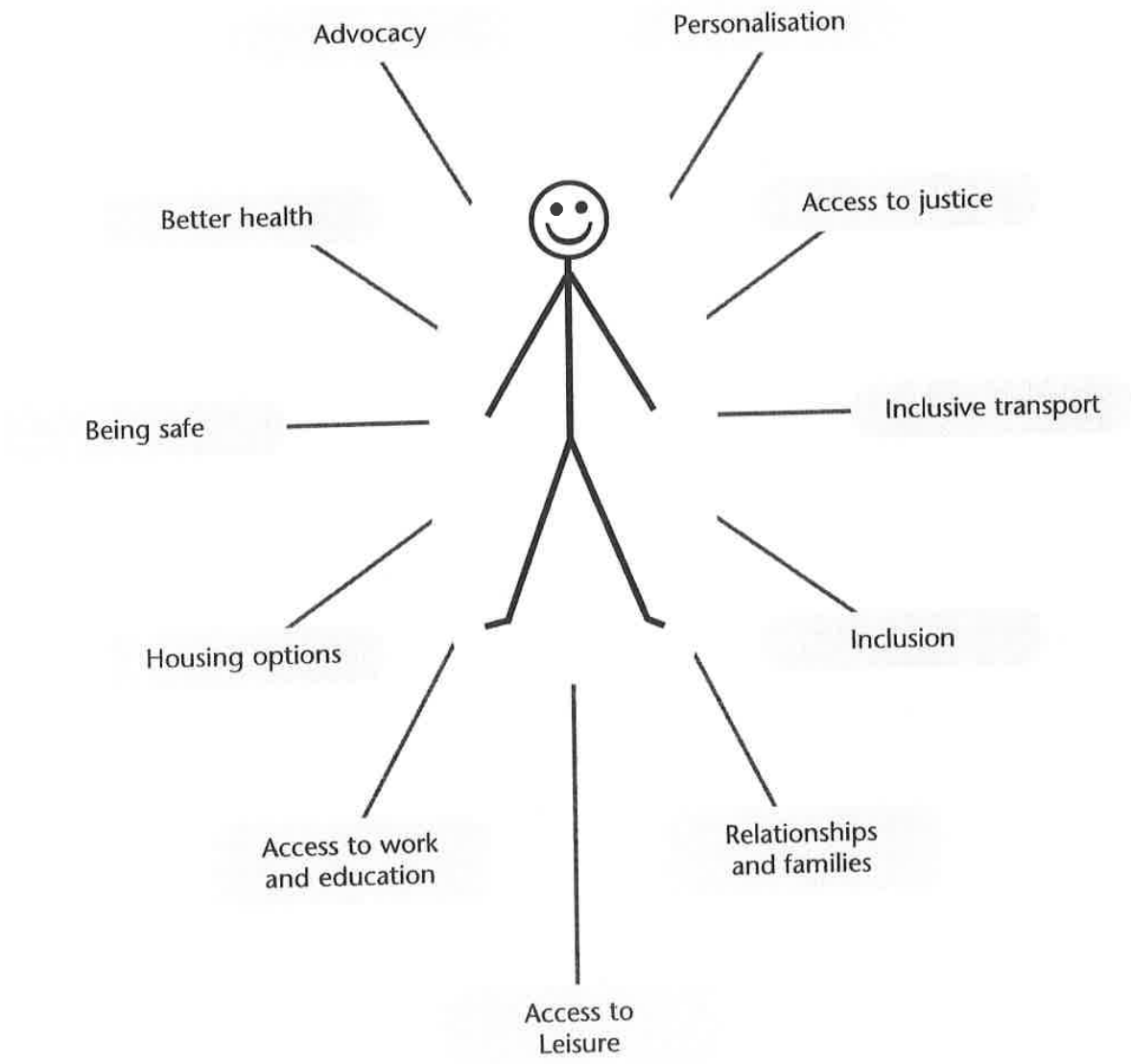
This can be represented diagrammatically as shown on the next page.

7.1 Service delivery principles

- Speech and language therapy service delivery is committed to the promotion of independence, choice, inclusion and civil rights.
  - Speech and language therapy service delivery considers communication and eating and drinking needs in the context of a social model of disability.
  - Speech and language therapists are committed to delivering their services in line with the personalisation agenda. Interventions are linked to the life aims and identified priorities of individuals.
  - Speech and language therapy service delivery to adults with learning disabilities is in line and in partnership with local policies, resources, and priorities.
  - Speech and language therapists value, respect and promote all modalities of communication.
  - Speech and language therapy service delivery maximises service user involvement at all levels.
  - A collaborative approach to service delivery across agencies, professional groups and also across the lifespan of the people with learning disabilities is essential.

(Adapted from the first RCSLT ALD Position Paper, 2003)

7.2 Person-centred values
(adapted from Valuing People, Valuing Employment Now, Equal Lives, Same as You and Fulfilling the Promises)



8. Role and scope of practice

The following model was used as a guide at the position paper consultation events as a way to gain consensus about the role and scope of practice of SLTs.

Using a triangle to describe tiers of health and social care is a widely utilised conceptual framework. Tiers can be interpreted differently between agencies and care groups. However, it is widely recognised that services can be mapped out usefully in this way, eg NHS and Social Care model for long-term conditions (2006), Learning Disability Services Commissioning Partnership Wales (2008).

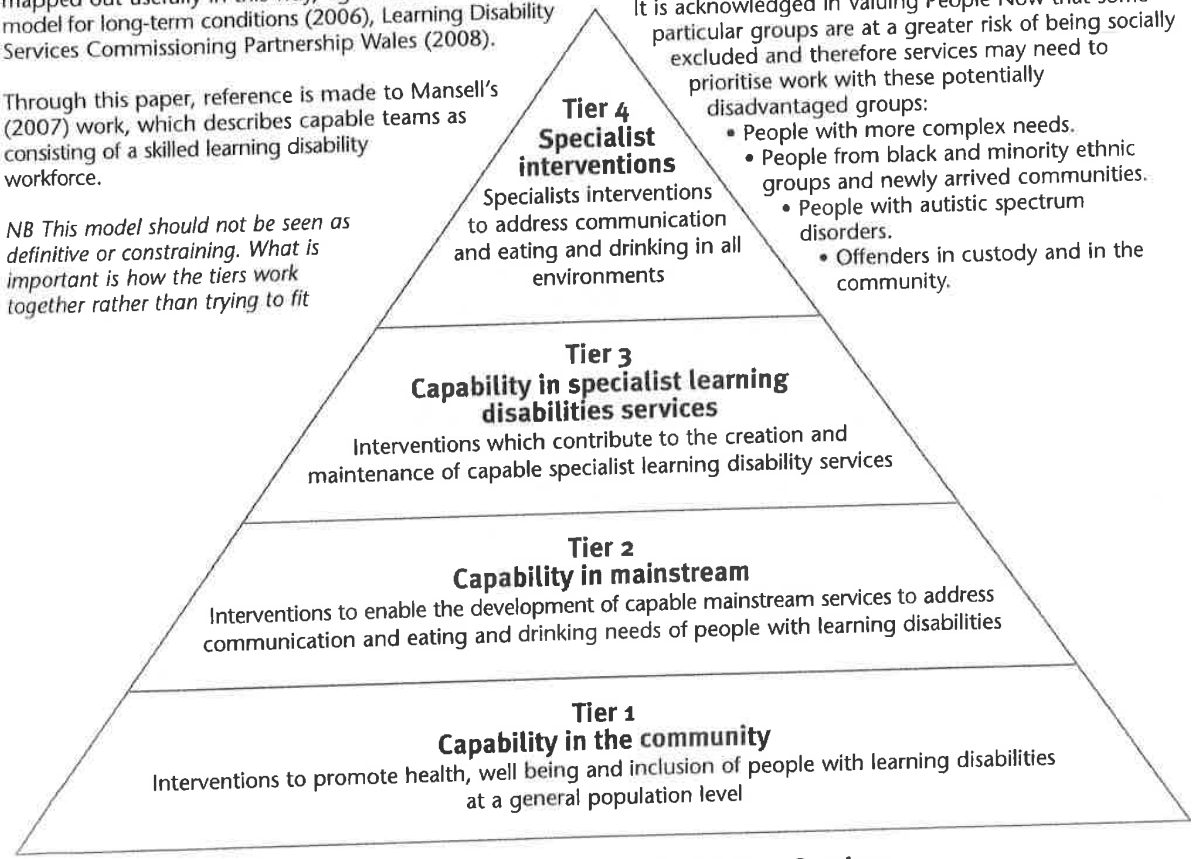
Through this paper, reference is made to Mansell's (2007) work, which describes capable teams as consisting of a skilled learning disability workforce.

NB This model should not be seen as definitive or constraining. What is important is how the tiers work together rather than trying to fit services into each tier. Also, people can be in need of more than one tier at one time depending on their circumstances at a particular time and individual needs.

The position paper acknowledges that the way speech and language therapy resources are allocated across the tiers will vary according to local priorities and commissioning arrangements and service capacity.

It is acknowledged in Valuing People Now that some particular groups are at a greater risk of being socially excluded and therefore services may need to prioritise work with these potentially disadvantaged groups:

- People with more complex needs.
- People from black and minority ethnic groups and newly arrived communities.
- People with autistic spectrum disorders.
- Offenders in custody and in the community.



Tiered Model of Health and Social Care Services

Adapted for speech and language therapy service delivery in adult learning disability services

Adapted from Specialist healthcare services – a tiered view.

Department of Health commissioning guidance – Tiered model of UK H&S Services p.185 CQ3 (2006)

8.1 Capability in the community

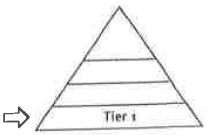
Communication disability is cited in all key strategic drivers across the UK (Valuing People Now, 2008; Equal Lives, 2005; Same as You, 2000; Fulfilling the Promises, 2001), as a reason why people with a learning disability can be socially excluded or marginalised from their own communities. Disability, Equality and Human Rights legislation (Disability Discrimination Act (DDA) 2005; Human Rights Act, 1998; Section 75 of the Northern Ireland Act, DDO, 2006; A Life Like No Other, 2007) has meant universal services must not be discriminatory in their practices (DDA, 2005). Valuing People Now (2009) as well as the aforementioned UK strategic drivers, cite the key areas of 'having a life' as being:

- Better health.
- Housing.
- Work and education.
- Relationships and having a family.

Working with universal service partners to improve awareness and knowledge of ways to overcome communication difficulties should therefore be a core role of SLTs.

There has been considerable work carried out nationally regarding this tier. Unfortunately very little research has been published which demonstrates the value of speech and language therapy intervention in improving social inclusion. However, there is considerable consensus and anecdotal evidence from projects across the UK that suggest that this work is considered as offering significant benefit.

This tier of the model describes the role of speech and language therapy in improving knowledge and skills at a community level to understand and best support the



communication needs of people with a learning disability. It also includes work to raise understanding of the needs of people with a learning disability who require modified diets, eg modified diet choices in local cafes.

Depending on local need and resources, partnerships will vary. However, key priority partnerships agreed by consensus nationally include:

- Police and emergency services.
- Transport agencies.
- Leisure industries.
- Retail industries.
- Restaurants and cafes.
- Further education.
- Employment and housing.
- Substance misuse services.
- Religious and faith organisations.

Speech and language therapists in England should be aware that Valuing People Now (2009) cites the importance of working with transport providers, leisure services and social activities to ensure these services take into account the needs of people with learning disabilities.

In Scotland an informal alliance called Communication Forum Scotland has been set up representing people of all ages with varied communication support needs. Its aims are to highlight the diverse range of communication support needs and promote ways of meeting these needs.

Tier 1 – Capability in the community – expected outcomes and risks
Communication and eating/drinking/dysphagia

Expected outcomes of providing a specialist speech and language therapy service include:

- Increased positive regard for people with learning disability.
- Increased awareness and examples of Total Communication practice.
- Increased examples of positive experiences by people with learning disability in accessing everyday activities and places, eg library, cafe, shops.
- Feeling safe and valued in the community, eg safer places where people can access help.
- Increased job opportunities.

Risks of not providing a specialist speech and language therapy service include:

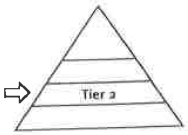
- Increased stigma.
- Increased vulnerability to abuse and hate crime.
- Withdrawal from community life, eg not eating out.
- Failure to meet legal requirements of:
  - Mental Capacity Act
  - Human Rights Act
  - Disability Discrimination Act

Reasonable adjustments not made in the community, eg pureed food not provided
People with communication and learning disabilities are unable to access job opportunities.

In South Devon and Torbay SLTs have been very involved in an innovative community project regarding a safer place to live scheme.

- Interagency and multidisciplinary working between Devon and Cornwall Police, other emergency services and the Learning Disability partnership and provider services agreed to produce an update to Hertfordshire's "People in Partnership (PiP) Pack. Rebranding and expanding the pack to include wider issues of "keeping safe".
- This resulted in the "Keeping Safe Pack" which is being produced through Pluss, a social firm training and employing people with a learning disability. They have produced a website about the pack www.keepingsafe.org.uk
- During the work, a local chamber of commerce group approached the steering group to ask how they could support people in their community who were being bullied or became victims of hate crime. The "safe place" scheme was born from this request, with speech and language therapy designing shop window stickers, simple cards for people to carry reading "I need help" and a help sheet for shop keepers, using pictures to help bridge the communication gap when trying to explain what happened and who needs to be called. This scheme is being rolled out across Devon and Cornwall by the Police Community Support Officers. Other areas have expressed an interest in the scheme.

In the Abertawe BroMorgannwg NHS Trust the SLT has worked jointly with local housing associations to develop an accessible tenancy agreement for service users to understand their tenancy rights and to enable them to express their opinions in relation to their accommodation.



8.2 Capability in mainstream

Work at this tier focuses on interventions to support mainstream services, eg hospitals, primary care, to make reasonable adjustments in relation to communication as required by DDA (2005) and as recommended in key documents, eg Healthcare for All (2008), Equalities (2005). Key partnerships at this tier would include primary and secondary healthcare staff, criminal justice workers, child and family services, further education colleagues.

Whilst this tier includes all 'mainstream' services, eg criminal justice system, family courts, the position paper would suggest that SLTs have a fundamental role to play in partnership with others, to address healthcare inequalities as a national priority.

Speech and language therapists have a role to improve the awareness and understanding of primary and secondary healthcare staff of the needs of people with a learning disability and communication/dysphagia needs and working with them to improve access. For example, training GPs, ward staff, community palliative care teams, community rehabilitation teams, health promotion staff, family and childcare teams, mental health teams.

If a person with a learning disability develops communication problems relating to a neurological or other medical condition, they should have access to the speech and language therapy services that specialise in that condition.

This is in line with all UK governments' policies that people should be receiving mainstream provision where possible, with specialist advice sought if necessary.

Key factors to be considered regarding how people with a learning disability would access mainstream adult speech and language therapy services will include:
- The complexity of the person's learning disability.
- The impact of this on their ability to access the service.
- The capability and capacity of the service.

The specialist adult learning disability SLT's role will vary from no involvement through to advice, training and supervision, partnership working or working alongside the mainstream speech and language therapy service.

Specialist adult learning disability therapists have a core role to play (as with other mainstream health services) in developing the understanding, capability and competencies of mainstream SLTs in working with people with a learning disability.

In Portsmouth City PCT Specialist ALD speech and language therapy services are fully integrated with mainstream speech and language therapy. Each person is considered at the time of his or her referral. Both communication and dysphagia are triaged and cases allocated to mainstream or specialist ALD speech and language therapy based on clinical need.

In addition, the education of undergraduate and post-graduate staff is a recommendation from Healthcare for All (2008). SLTs are in a key position to offer and advise on training that develops the awareness of the communication and eating and drinking needs of people with learning disabilities.

The SLTs working in the Northern Trust, Northern Ireland have developed a joint project with A&E staff. "Come & See A & E" SLTs provided training to A&E medical and nursing staff in communicating with adults with learning disabilities. Training sessions included the use of practical strategies such as signs and visual cues when working with ALD in order to assist with difficulties that may arise such as establishing the nature of the medical complaint and pain location. They also co-coordinated visits to the A&E department for service users so that they could experience the environment and procedures, eg having casts fitted to limbs, in a relaxed and supportive environment.

The learning disability speech and language therapy team in Eastern Kent and Coastal PCT have a collaborative project with the radiographers at the Breast Screening Unit at the Kent and Canterbury Hospital. In order to improve the uptake of breast screening amongst women with a learning disability they have:

- Changed the policy of the breast screening unit so women with learning disabilities are offered appointments at the hospital instead of the mobile units. They are also allocated a half hour appointment instead of the six minutes offered to most women.
- Produced a 'user friendly' leaflet with photographs of the unit.
- All unit staff, from receptionist to senior radiologist have been trained in communication strategies and the relevant Makaton signs.
- Made photographic resources available in each room and mobile unit detailing the breast screening process.
- Raised staff awareness of consent issues.

They are currently developing photographic resources describing the process of investigation, should an abnormality be detected.

In addition to more general services, speech and language therapy work has successfully been targeted to known high risk/common health issues for people with a learning disability, eg videofluoroscopy clinics, audiology and ENT.

All primary and secondary health care work should be delivered in partnership with health care providers. Key priority partnerships agreed by consensus nationally include: audiology, gastroenterology, GPs, practice nurses, hospital liaison staff, maternity services, ophthalmology, patient advice and liaison services, mainstream speech and language therapy, complementary therapies, mental health, dental and oral hygiene staff.

In the Camden Learning Disability Service the SLT has developed an accessible Care Programme Approach (CPA) tool kit with a multidisciplinary steering group to support users to participate and understand the CPA process.

An SLT working in Oxleas NHS Foundation Trust has developed a protocol between community ALD speech and language therapy and acute hospital speech and language therapy for joined up working regarding videofluoroscopy/percutaneous endoscopic gastrostomy. The protocol outlines the steps that speech and language therapy services will take when working with individuals with severe/profound dysphagia. It ensures consistent experiences for the service users and informs carers/staff what to expect at each stage.

The way resources are allocated at this tier will be dependent on local speech and language therapy resources and commissioning priorities.

Tier 2 – Capability in mainstream – expected outcomes and risks
Communication and eating/drinking/dysphagia

Expected outcomes of providing a specialist speech and language therapy service include:

- Reduced healthcare inequalities.
- Evidence of mainstream services being adapted to include people with learning disability, eg audiology and vision services; videofluoroscopy; criminal justice system.
- Improved patients' understanding, choice and control through a care-pathway.
- A positive experience for people with learning disability and their carers.
- People with learning disabilities have their needs met by primary and secondary healthcare services, with specialist support where necessary.
- Improved health and life expectancy.
- Prevention of unnecessary hospital admissions.

Risks of not providing a specialist speech and language therapy service include:

- Increased anxiety and distress for people with learning disability and their families/carers during hospital admissions.
- Lower standard of healthcare received as communication and eating and drinking/dysphagia needs are not adequately addressed.
- Overuse of specialist learning disability services when mainstream services should provide adequate care.
- Failure to meet legal requirements of:
  - Mental Capacity Act (England)/Incapacity Act (Scotland)/Good Practice in Consent (Northern Ireland)
  - Human Rights Act
  - Disability Discrimination Act
- People not making informed decisions, eg lack information in understandable formats.
- Increased vulnerability of abuse.
- Preventable death, eg undiagnosed dysphagia.

8.3 Capability in specialist learning disability services

National guidance, eg Valuing People Now (2009), Equal Lives (2005), The Same As You (2000) and Fulfilling the Promises (2001), suggests that it is a fundamental role of learning disability teams and therefore SLTs, to work with partner agencies to improve specialist services for people with a learning disability. Despite the move to more integrated and mainstream provision, currently people with a learning disability receive many of their services from specialist care providers.

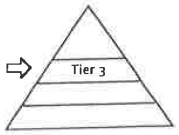
In the consultation events all SLTs agreed nationally that strategic and targeted work in this area is core business.

Work at this tier aims to:

- Improve knowledge and skill of the learning disability workforce in understanding and responding to people with a learning disability with communication difficulties.
- Improve knowledge and skill of the learning disability workforce in understanding and responding to people with a learning disability who have eating and drinking difficulties/dysphagia.
- Ensure environments focused on the needs of people with a learning disability are capable to meet the needs of people with communication difficulties and dysphagia.
- Develop responsive environments that support inclusive communication and empower individuals.

An SLT in NHS Forth Valley has championed 'SNACK':

There was a significant concern over the health needs of clients with a learning disability and eating and drinking difficulties. The role of carers in managing these issues was recognised as crucial. Similar information was being gathered by Community Learning Disability Team (CLDT) members on several occasions. It was recognised this required a more strategic and coherent approach to impact on clinical effectiveness. A multidisciplinary training package called Safe Nutritional and Chewing Knowledge (SNACK) was developed so that an SLT or dietitian could run with another trained member of the CLDT. The purpose of SNACK was to provide quality training that acknowledges the shared professional responsibilities in providing safe eating and drinking support.



Speech and language therapy provision at this tier of the model may include any one or more of the following:

- Accessible/inclusive communication environments, eg objects of reference/signing/visual timetables/promoting use of easy read resources.
- Supportive and responsive communication environments, eg Intensive Interaction.
- Training staff, eg signing/Talking Mats/communication passports.
- Consultation/non-direct advice and support, eg drop ins.
- Consultation to improve personalised care, eg person-centred planning and toolkit, direct payments/individual budgets.
- Being active members of partnership boards or equivalent to advise on communication issues, eg workforce development subgroups/person centred planning/total communication projects/transition.
- Supporting/leading development of service-wide communication and/or eating and drinking strategies.

Speech and language therapy services at this tier would be delivered in partnership with:

- People with learning disabilities (peer supporters as well as individuals who need support) and families.
- CLDT colleagues (health and social care).
- Group homes (health, social care, independent and voluntary sector).
- Day opportunities, specialist employment agencies, specialist local learning disability provisions.
- Local advocacy services.
- Independent mental capacity advocates – local IMCAs (England and Wales).
- Partnership boards and equivalents.

Speech and language therapy services would also be delivered in line with recommendations from national guidance from the following organisations and regulatory bodies – MENCAP, British Institute of Learning Disabilities (BILD), Scottish Consortium for Learning Disability (SCLD).

Tier 3 – Capability in specialist learning disability services expected outcomes and risks
Communication and eating/drinking/dysphagia

Expected outcomes of providing a specialist speech and language therapy service include:

- People with learning disability will access a quality environment.
- Staff will have appropriate skills to suit the communication and eating and drinking/dysphagia needs of the service users.
- Compliance with the requirements of Valuing People Now, Same as You, Equal Lives, Fulfilling the Promise.
- Evident understanding of the communication needs of people with learning disability.
- Appropriate and timely referrals for eating and drinking/dysphagia.
- Improved quality of care provided through supervisory support.
- Evidence of Total Communication/Inclusive Communication practice.
- Non-verbal signals of distress recognised and responded to.
- Consistent, stable placements and staff team.

Risks of not providing a specialist speech and language therapy service include:

- Services fail to achieve national quality standards.
- Inadequate or incomplete specialist learning disability care-pathways.
- People's placements may break-down due to lack of staff competence in understanding and responding to communication and dysphagia.
- Increased vulnerability of abuse and safeguarding issues.
- Increase in number of incidents that need to be reported.
- Increase number of inappropriate referrals at Tier 4.
- Increase in challenging behaviour.
- Increase of injury and distress for service users, families and carers.
- Preventable illness and death.

An SLT in London has developed a bespoke communication support-training package for a housing service specifically for people with learning disability.

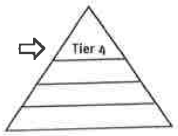
To increase the awareness and skills of housing support officers, working for the organisation, in appropriate communication support methods to use with the individuals whom they support.

To develop and deliver a number of practical-based communication support training sessions. These were tailored to the needs of clients supported by the housing officers within this organisation and covered topics such as:

- General communication strategies when supporting an individual with a learning disability.
- Communication strategies when supporting an individual with a learning disability and a sensory impairment.
- The use of visual supports to support communication.
- The use of keyword signs to support communication etc.

Each session was held at the organisation's office base and used practical exercises related directly to the role of the housing officers in receipt of the training.

8.4 Specialist interventions to address the needs of individuals



This tier describes the core business of SLTs in community learning disability teams to provide assessment, information and training/advice for individuals with a learning disability and complex communication needs or dysphagia referred to the service. Eligibility criteria for the service will be decided locally. More detailed information can be found in key RCSLT guidelines eg CQ3, Clinical Guidelines, Competencies Project (2003), in relation to this area.

Process

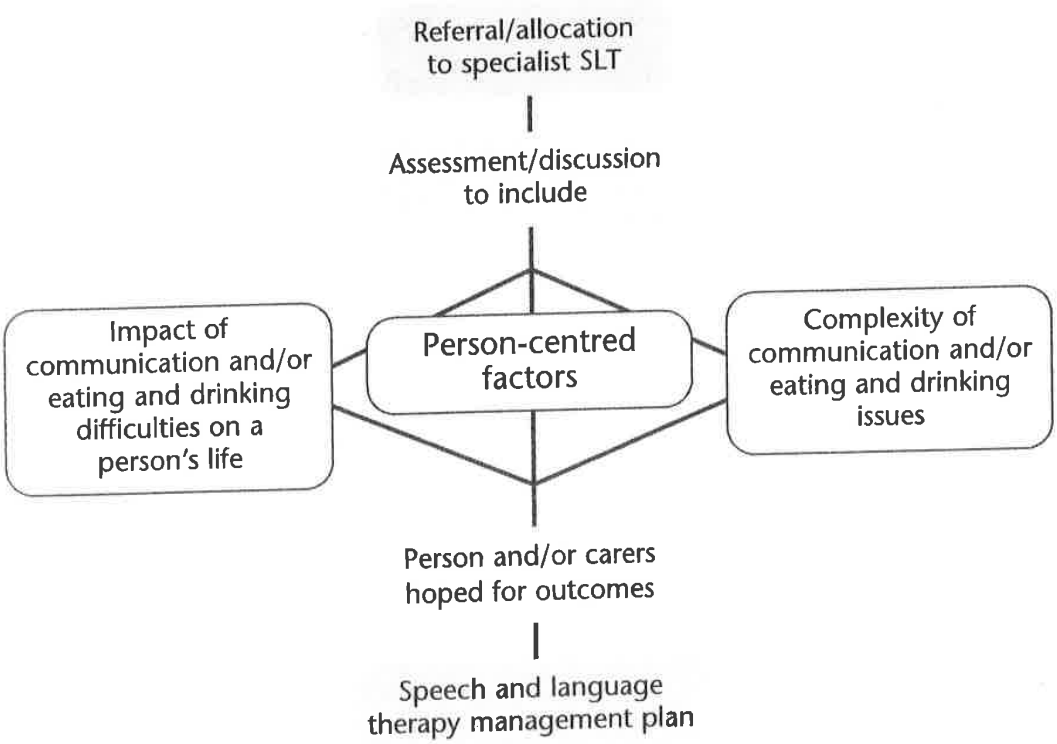
Adapted from the first RCSLT ALD position paper, 2003.

The SLT must deliver personalised services, working with the individual and their significant others.

A variety of approaches are likely to be used, and these may include one or more of the following:

- Assessment and evaluation.
- Producing a formulation based on this evaluation and devising a plan with clear objectives.
- Advice/consultation/co-working with others including families.
- Training/teaching/transmitting information.
- Coaching/enabling/resourcing.
- Improving overall communication environments.
- Use of specialist knowledge and skills to facilitate and inform the work of other professionals.

In line with national best practice in relation to person centred outcomes, the following process should be applied to all referrals:



Being person-centred from the outset in clarifying the reason **why** a speech and language therapy referral has been made, the impact on the individual's life and the hoped for outcome(s), enables everyone concerned to determine what speech and language therapy intervention(s) will be the most useful and effective.

The following describe key areas of an individual's life that may need speech and language therapy support (agreed at the national consultation events):

- Behaviours which challenge/prevention of violence, aggression and distress.
- Safeguarding issues.
- Issues for parents who have learning disabilities.
- Differential diagnosis.
- Relationship issues.
- Social skills.
- Housing.
- Employment.
- Leisure.
- Sexuality/sexual health.
- Transition.
- Consent.
- Dysphagia.
- End of life care.
- Specific 'access' issues, eg blood tests.
- Forensic/offending behaviour.

Speech and language therapy in Leicester Partnership NHS Trust has been working within a multidisciplinary team to enable some parents with learning disabilities to engage fully in assessment of their parenting capacity, improve the communication skills of those working with them, and help them understand the child protection process. The outcome was that the child was removed from the child protection register and appropriate support given to the parents.

- A full speech and language therapy assessment was carried out with both mum and dad and this information shared.
- Speech and language therapy worked with the family aide worker around issues of weaning/ feeding children appropriately and routines.
- Recommendations of the child protection case were made accessible to the parents to ensure their understanding and participation in the process.
- Joint visits were undertaken with children's social workers to give an opinion on the parent's understanding of complex verbal information.
- Joint working with the community LD nurse to develop skills, eg shopping, cooking, budgeting.

Speech and Language therapy had a major role in highlighting how the parent's communication needs impacted on the parenting assessment.

It is in line with national best practice, eg Challenging Behaviour – A Unified Approach (2007) that all speech and language therapy assessments will be part of a multidisciplinary approach.

The work at the other tiers will help to ensure the referrals we accept at this level are the ones that are appropriate for this level of intervention, for example where speech and language therapy can be effective. The work at the other tiers also allows the progress made at the individual level to be sustained and maintained across a range of settings.

In Northampton the Speech and Language Therapy in the Community Team for People with Learning Disabilities (CTPLD) describes work in relation to the need for a client to have a possible per endoscopic gastrostomy (PEG) insertion.

Speech and language therapy met with service user and his carers to discuss swallowing difficulties and possibility of PEG insertion. Speech and language therapy then liaised with GP to request referral to gastroenterologist and attended gastroenterology appointment with carer, as service user was having difficulties using his wheelchair and therefore could not attend appointment as arranged. As there were ongoing issues with service user attending hospital appointment, speech and language therapy liaised with service user and gastroenterologist in order to ensure service user understood information from gastroenterologist and that the service user's questions regarding the PEG were answered. After the service user had made the decision to go ahead with PEG insertion, speech and language therapy liaised with strategic health facilitator for the local hospital to ensure provision was made on the ward for service user's needs to be met and for his carer to stay with him during admission. Speech and language therapy also liaised with community nurse support worker who ensured that a "Helping me in hospital" book was developed prior to admission and with the dietician and nutrition nurse to ensure follow up care was in place.

Tier 4 – Specialist interventions – expected outcomes and risks
Communication

Expected outcomes of providing a specialist speech and language therapy service include:

- Specialist speech and language therapy interventions result in person-centred communication strategies tailored to meet an individual's needs and maximise their abilities and opportunities and enjoyment of rights.
- Increase in meaningful engagement and interactions.
- Improvement in emotional and mental well being.
- Improvement in inclusion of people with more severe disability and PMLD.
- Improved transition.
- Reduction in frustration and distress of individual and others.
- Crisis prevention.
- Improved access to the safeguards and protections in criminal justice system.

Risks of not providing a specialist speech and language therapy service include:

- Placement breakdown.
- Inpatient admission.
- Out of county placement.
- Vulnerability to breakdown in mental well being.
- Increased vulnerability and safeguarding issues.
- Exclusion.
- Offending.
- Increased challenging behaviour.
- Failure to meet legal requirements of:
  - Mental Capacity Act (England)/Incapacity Act (Scotland)/Good Practice in Consent (Northern Ireland)
  - Human Rights Act
  - Disability Discrimination Act

Tier 4 – Specialist interventions – expected outcomes and risks
continued Dysphagia

Expected outcomes of providing a specialist speech and language therapy service include:

- Specialist speech and language therapy interventions result in person-centred, individually tailored support that maximise and individual's abilities and opportunities for safe and enjoyable eating and drinking.
- Improved life expectancy.
- Improved physical health.
- Improved emotional well being.

Risks of not providing a specialist speech and language therapy service include:

- Choking.
- Aspiration.
- Dehydration.
- Malnutrition.
- Increased incidence of chest infection and subsequent demand on primary care resources.
- Compromised health.
- Repeated or prolonged hospital admission.
- Distressing and unnecessary medical procedures.
- Premature/preventable death.

9. Accessible information

The term 'accessible information' is now widely used within national documentation and it is accepted by all as an essential element of supporting the communication needs of people with learning disabilities. It is the general term used to describe making information easier to understand for people with people with learning disabilities. Over the last decade we have seen the emergence of various terminologies that are all used to describe similar methods of support such as; Inclusive Communication, Total Communication, easy read etc. Whilst all of these support the communication needs of people with learning disability, the distinction needs to be made that accessible information is aimed at supporting **receptive** communication needs. The term 'accessible information' is applicable to all levels of receptive communication from sensory information through to text based information; rather than 'easy read' which just refers to access to the written word. Accessible information can therefore be defined as:

> *'A supportive process of making information easier for people with learning disabilities, that firstly involves simplifying the linguistic message and secondly conveying the simplified message in different mode(s) of communication, ie not just the written word or spoken message'*
>
> (Mander, 2008)

It is important that accessible information is seen as a process with various stages of production and implementation, rather than just an accessible resource, as without the implementation of such resources, accessibility is not necessarily improved.

The rationale for accessible information is not only considered best practice, but within the UK it is set within a legal framework. Firstly, the Disability Discrimination Act (1995) stipulates that 'reasonable adjustments' need to be made to improve access for people with disabilities and the Human Rights Acts Article 10 (1998) sets out the right to information as does the Communication Bill of Rights (1992). The Mental Capacity Act (1998) highlights the need for 'practicable steps' to be taken to support individual communication needs with reference to the decision making process. More recently Valuing People (DoH, 2001) and Valuing People Now (DoH, 2009) state that the government expects organisations working with learning disabled people to develop communication policies and produce and disseminate information in accessible formats.

At a practical level, one of the most important considerations is individual differences. As we know, it is not possible to neatly categorise the receptive communication needs of the population and this is the quintessential challenge in supporting their receptive communication needs through the use of accessible information. Accessibility is not absolute. What counts as accessible for one person will not necessarily be so for someone else. Extreme individual differences are just one aspect that influences the multi-faceted nature of accessible information and the unlikelihood of the production and implementation of accessible information being a straightforward process.

As stated above, accessible information is an issue for everyone and not solely the role and responsibility of speech and language therapy. When we consider our role in the production and implementation of accessible information it will depend greatly on local needs and the resources available. At a specialist clinical tier, assessing and supporting an individual's receptive communication needs through the use of tailored accessible information will be relevant to all. At the other tiers of the model, working in partnerships with other agencies is essential; this may include a wide range of learning disability services through to media and communication departments. Below you will find some suggested roles and responsibilities at each level:

Tiers 1, 2 and 3: community, mainstream and specialist teams

When we consider accessible information at these levels, a high degree of person-centeredness is hard to achieve, in that it is not possible to produce one resource that will meet the needs of the whole learning disability population. With this in mind speech and language therapy may have a role in:

- Promoting the use of accessible information to support receptive communication needs.
- Developing written guidelines/local strategies/training about how to produce and implement accessible information.
- Reinforce the legal context of accessible information and the responsibility of accessible information.
- At a strategic level, involvement in planning/promotion of the use of accessible information.
- Acting as a consultant to organisations producing accessible information is terms of appraisal of the information.
- Signposting others to relevant materials/internet sites.

Tier 4: Individual tier

At a specialist clinical level, accessible information should be tailored to the individual and therefore complement their communication skills and needs. At Tier 4, the SLT may have a role in:

- Identifying communication strengths and needs, to include: level of symbolic development, sensory impairments, comprehension levels etc.
- Producing or commissioning specific accessible information for the individual and supporting its implementation.
- Advising key worker/s, other professionals and carers on how to produce and implement accessible information for an individual.
- Supporting the translation of relevant information into an appropriate format, eg care plans.
- Training other professionals and care workers to tailor their communication and environment to cater specifically for the needs of individuals.
- Promoting the use of person-centred strategies and resources.

There will be forthcoming guidance from the Department of Health for people who commission or produce 'easy read' information.

10. Workforce development

Recent shifts in policy have required SLTs to examine their skills and competencies. The UK wide Skills for Health require the workforce to meet the needs of the service user by putting their needs before professional boundaries.

As a profession, SLTs need to develop emerging roles and be clear about the competences and skills required to meet that role. Speech and language therapists need to cross-traditional professional and agency boundaries and be open to workforce redesign.

This section will consider the evolving workforce and put forward consensus views on workforce development.

There are detailed guidelines on clinical practice in RCSLT Clinical Guidelines (2005), RCSLT Competencies Project (2003) and CQ3 (2006). This section is not intending to repeat these guidelines. It is not the remit of a position paper to discuss competencies and capability.

During consultation events held across the UK, participants were asked to consider the evolving roles and workforce issues for therapists and assistants/support workers working in the area of ALD.

Recent shifts in learning disability policy require SLTs within the field of ALD to work in innovative and creative ways. These emerging roles are not outside of the scope of core professional practice and are still considered 'core business' for ALD SLTs.

The RCSLT Policy Statement 'Evolving roles in speech and language therapy' (October 2008) provides a framework for RCSLT members who roles may be evolving or who may be setting up new clinical initiatives. ALD is a rapidly expanding area and it is apparent that SLTs working within this clinical area are developing new roles and skills. This development should take place within a safe framework endorsed by the RCSLT and which is in the best interests of clients.

An overall policy objective in Valuing People Now (2009) is "The workforce across public services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver the Valuing People Now priorities for all people with learning disabilities."

During consultation events the following emerging roles were identified:

- Criminal justice system including intermediary and community forensic services.
- Developing role with people with dementia.
- Parents with learning disabilities (working alongside children's services).
- Complex dysphagia management.
- Autistic spectrum disorder (including Asperger's).
- Mental health.
- Palliative care.

The emergence of different roles or ways of working "should not be limited by the grading of the clinician and may not always be exclusively developed and carried out by advanced practitioners" (Evolving Roles in Speech and Language Therapy, RCSLT. October 2008). It is possible for all levels of the speech and language therapy workforce to work in any of the above. What needs to be considered is the level of support available, the skills needed for the role, the competencies required by the role and the capability of the speech and language therapy in that role.

10.1 Skill mix and the role of the speech and language therapy assistant practitioners/ support workers

The speech and language therapy assistant/support worker is an integral member of the speech and language therapy team and is employed to act in a supporting role under the direction of a professionally qualified speech and language therapy (CQ3 2006). In addition to this is the developing role of the generic worker. Further information on skills and competencies for assistants/ support workers can be gathered from CQ3, NHS, KSF, RCSLT Support Practitioner Core Clinical Competencies (2002) and the RCSLT Policy Statement on Education and Training for Assistants/Support Workers (2009).

The RCSLT Policy Statement 'Education and Training for Assistants/Support Workers' (2009) affirms there are changing demands within health, education and social care and there is increasing status, responsibility and accountability expected of assistants/support workers.

The role of the Assistant/Support Worker within ALD speech and language therapy services mirrors that of therapists in that there is a need to broaden the scope to remain inline with key national drivers. Consultation events showed there is a varied and diverse role for assistant practitioners/support workers within UK ALD speech and language therapy services (See paragraphs 10.2/10.3).

10.2 Existing role of assistant practitioners/support workers

- Producing client resources using advanced IT knowledge, eg to produce passports, life story book.
- Jointly running groups.
- Observational assessment.
- Participating in and supporting training.
- Supporting production and implementation of accessible information.
- Carrying out interventions, eg intensive interaction (under direction of a qualified SLT).
- Tutors for Makaton, Signalong, or other signing systems.
- Supporting the implementation of augmentative and alternative communication (AAC).
- Promotion of team, eg at exhibitions.

10.3 Trends in emerging and existing roles

From the UK-wide consultation events it is clear to see that there are emerging roles for the assistant/support worker population. Whilst this broadening scope in practice will be dependant on local influences, the need for robust supervision and clear lines of accountability are paramount.

- Triage.
- Eating and drinking/dysphagia monitoring.
- Screening assessment and informal assessment.
- Development of specialisms within teams, eg Intensive Interaction, signing, dysphagia.

Workforce development is an important area for all SLTs to consider. The speech and language therapy workforce needs to be aware of national trends in workforce development and how this will impact on individual services. Speech and language therapists and speech and language therapy assistants have a broad range of skills and competencies that enable them to fulfil a number of different roles and commissioners need to be aware of the unique contribution of SLTs across LD services.

10.4 Building capacity of people with learning disabilities to enhance their contribution to service delivery

Work towards building capacity and developing an increasing partnership with people with a learning disability and their families. This approach recognises that the people with a learning disability are the people who are experts in what it is like to live with a communication support need and therefore can support a variety of projects, eg training staff, advising on accessible information, quality assurance activities. An example of the latter is reported in Cameron and Boa (2009).

11. The Future

Following development of this paper, the ALD Speech and Language Therapy network should consider the following questions:

- Should there be specific outcome measures for ALD?
- What performance indicators relate to the tiered model of health and social care described in this paper?
- What is the contribution of speech and language therapy to Payment by Results in England/Tariff-based commissioning?
- What is the optimal provider context for efficiency and effectiveness of speech and language therapy services to people with learning disabilities, eg health, social care and social enterprise?
- What are emerging roles for the speech and language therapy ALD workforce, to include qualified staff and assistant practitioners?
- What is the impact of individualised healthcare budgets on the delivery of speech and language therapy services?

12. Review of literature and level of evidence

Throughout this consultation process and in the writing of this paper there has been a thorough overview of relevant research and literature relating to ALD. Using the electronic survey tool the profession has been asked to highlight those key papers/projects that influence clinical practice. These are included in the reference list at the end of the document.



top Comms chart

centre Richard and Chayne have taken part in an involvement project in Leicester

bottom Reema shows her communication passport

Conclusion

This position paper aims to offer guidance to SLTs and others with a vested interest in delivering high quality services to people with a learning disability.

The paper is a collective view gained by consultation with the profession. It aims to offer a vision of the way speech and language therapy services for people with learning disabilities should be delivered.

We want to encourage SLTs and their employing organisations to embed this guidance into their policies, partnership agreements and their own working practices.



back row (from left to right) Christine Whitehead, Susan Jones, Pat Walker, Roberta Richards
front row (left to right) Heidi O'Neill and Kim Evans

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Notes

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National Standards for Practice-based Learning

January 2006

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NATIONAL STANDARDS FOR PRACTICE-BASED LEARNING

Rationale for the development of National Standards For Practice-based Learning

This document brings together what is already available in terms of standards and reflects the wealth of good practice across the UK.

Why?

1. This document is an opportunity to capture all standards in one place, endorsed by the professional body. Generic standards have been developed by external agencies such as the Quality Assurance Agency (QAA) and the Health Professions Council (HPC), but it is important to have speech and language therapy-specific practice-based learning standards.

2. This document aims to encompass all the necessary requirements of external quality assurance, so that adherence to these standards will meet requirements from all stakeholders.

Benefits to Higher Education Institutions

1. Universities have their own quality assurance protocols in place, which include practice-based learning, but these are usually generic. Profession-specific standards will enable universities to identify and monitor the quality of speech and language therapy placements.

2. These Royal College of Speech and Language Therapists (RCSLT) endorsed standards will enable universities to secure funding and resources for:

    - Placement coordinators and administrators;
    - Continued tutor support for placement learning, which is currently continuously being eroded;
    - Support/study days for placement educators;
    - Maintenance of essential links with other speech and

language therapy courses and with other health professionals.

3. The Standards will inform the design of pre-registration courses, which currently have practice-based education at their core. This is more essential than ever as multi-professional courses and new courses emerge, seeking HPC approval and RCSLT certification. Because the Standards relate to competencies and QAA Benchmarks, they will be a valuable source of reference to HEI staff writing practice-based education programmes, in order to ensure that students' practice-based education prepares them for the profession.

AIM

These Standards for Practice-based Learning aim to be an explicit articulation of the standards associated with all aspects of practice-based learning, involving all partners in the process: the higher education institution, the placement provider, individual placement educator and the student. The Standards are intended to ensure the patient/client is the central focus of the student's learning experience and that practice-based learning should foster a culture of reflective practice. They allow for different educational philosophies, but include a statement of the overarching values, beliefs and attitudes underpinning practice-based learning.

The terms used are as follows:

HEI refers to the higher education institution where the speech and language therapy pre-registration course is located.

Placement provider refers to the speech and language therapy service, which is providing the practice-based opportunity.

Placement educator refers to the individual speech and language therapist who is acting as the educator on the placement. *In a small service, the placement provider and the placement educator could be the same person.*

Student refers to the pre-registration speech and language therapy student who is undertaking practice-based learning opportunities, as part of his/her course.

Trust has been used as a generic term to identify the placement provider/educator's employing organisation.

VALUES, BELIEFS AND ATTITUDES

Whilst there is a consensus across the health professions on the importance of quality practice-based learning for students, there are also profession-specific values, beliefs, and attitudes, which are important to present at the beginning of any statement of profession-specific standards.

A core value is mutual respect for all partners. Central to this is a priority at all times for the well being of the patient/client and compliance with the ethical codes around confidentiality and consent.

Students are perceived, treated and respected as part of a collegiate partnership between HEI, placement providers and the individual placement educator. It is recognised that students bring value to the learning partnership.

It is appreciated that students will have an individual style and pace of learning and will participate in a range of learning opportunities with their placement educators, in order to develop appropriately across all key areas of competence.

Students are constructively supported by the HEI, placement providers and individual placement educators in the development of professional autonomy, professional and personal skills.

Students will move through the curriculum developing more self-direction and autonomy as they gain experience. The placement educator plays a central role in facilitating the student's learning opportunities. Part of the placement educator's role is to help the student access and apply relevant theoretical knowledge for practice. The placement educator will be appropriately prepared and supported

by the HEI for taking on this role, and for effectively managing the placement educator/student relationship.

THE FRAMEWORK

The framework is divided into six sections.

Section one
Practice-based learning and the curriculum
Includes curriculum design, organisation and content in respect of practice-based learning.

Section two
Preparation for placement
Includes all aspects of sourcing, selecting and assigning placements. It also includes activities before placements start, once they have been sourced and assigned.

Section three
The placement
This encompasses all activity during the placement, i.e. learning methods; patients/clients; range; difficulty; experience; dealing with difficulties. It also includes standards of assessment of student achievement of practice-based learning.

Section four
After placement
This includes debriefing, action if the student has failed to reach required standards and communication of outcomes.

Section five
Learning resources to support placement activity
This aims to reflect the physical resources, such as materials and library and human resources, including the HEI tutor, the placement educator and placement provider.

Section six

Quality monitoring, management and enhancement

This section is not the only place where quality management and enhancement standards are located. These pertain to procedures arising once placement ends.

Within each section, the standards appropriate and most relevant for HEIs, placement providers and placement educators, and students are stated, under their own sub-section.

1. SECTION ONE
PRACTICE-BASED LEARNING AND THE CURRICULUM

Higher education institution

1.1. The HEI is responsible for determining all aspects of course design and delivery, and ensuring that the learning outcomes of a pre-registration speech and language therapy course can be met. This will be planned, developed and implemented in collaboration with placement providers and placement educators.

1.2. The course will have an integrative approach to the application of theory and practice, in line with the QAA Speech and Language Therapy Benchmark and the HPC Standards of Education and Training underpinned by RCSLT's curriculum guidance.

1.3 The HEI will work in partnership with placement providers and placement educators in the design, documentation and implementation of practice-based learning, including the timing of placements.

1.4 The HEI will have a clear statement about the student's responsibilities to fulfil the requirements of practice-based learning.

1.5 The HEI will have agreed policies for dealing with issues or difficulties that could arise as a result of the practice education. These policies will provide guidance on the procedures to be followed and the support available to each placement partner.

1.6 The HEI will provide guidelines for supporting all placement partners when a student does not reach the practice-based learning standards.

1.7 Courses are designed with different exit points during the duration of the course. Students who decide that speech and language therapy is not a suitable profession for them, will be able to exit at specified points, with academic credit (i.e.

successful academic award), without having to successfully complete a placement or redo a failed placement. This may include changing courses.

1.8 HEIs will make it explicit that a student, described at 1.7, will not be eligible to be a certified member of RCSLT or eligible for registration from HPC.

1.9 The course regulations will allow students' resit opportunities, in line with the HEI's regulations.

2. SECTION TWO
PREPARATION FOR PLACEMENT

All partners

2.1 All parties in the placement education process should be aware at all times of risks that occur in normal working environments and assess risk as appropriate following NHS and HEI guidelines.

Higher education institution

2.2 Sourcing, selecting and allocating placements are normally the responsibility of the HEI, devolved to the placement co-ordinator. This involves establishing networks and liaising with placement providers and students.

2.3 Local policies and procedures will be agreed between the HEI and the placement provider with respect to time scales and methods of communication, including alerting the Placement providers in appropriate time as to the likely number of placements that will be sought during each academic year. Also, timing for completion of documentation will be made by the HEI.

2.4 HEIs will seek input from local placement providers when designing placements in order to maximise capacity.

2.5 The sourcing of placements will also include options for additional placements required for failing students or those required to have additional practice-based learning opportunities.

2.6 Where students are involved in sourcing placements, selection procedures will be made clear by the HEI.

2.7 Where a student has a disability, the HEI will be advised by the HEI's disability adviser on how best to meet the placement learning needs of the student. The HEI will inform placement providers of any known issues. This will involve liaison with the student and agreement on disclosure of any issues that would impact on the risk assessment of the student's practice-based learning.

2.8 The HEI will make clear the requirements for working within the approved codes of ethics, police checks, and health and safety issues. This may involve the provision of forms and checklists for students and placement educators.

2.9 The HEI will be responsive to the risk assessment of specific placement locations and patient/client groups.

2.10 The HEI will inform students as to their role in risk assessment, including their responsibilities in alerting the HEI to any changes in circumstances.

2.11 The HEI will provide guidance for students on how to best prepare for placements practically, academically and professionally.

2.12 The HEI will provide a pre-placement briefing for students with supporting documentation.

2.13 The HEI will provide guidance for placement educators on how to facilitate students to learn most effectively while on placement. This will include guidance on the process and timing of feedback throughout the placement. It will, where appropriate, provide individual student-specific information.

2.14 The HEI will specify the timing and form of monitoring and feedback required between the placement educator and student. Specific documentation will be provided by the HEI to facilitate this process.

2.15 Where several placement educators are involved in a placement, the HEI will specify the recommended maximum number of placement educators. Exceptionally, where the number is exceeded, it will be recognised that further liaison will take place between the HEI tutor, student and placement provider.

2.16 The HEI will provide clear guidelines and procedures that the placement provider, placement educator and student follow when a student experiences difficulties.

2.17 The HEI will, in partnership with the placement provider, provide training for placement educators in practice-based learning. This will be in the form of an initial training followed by on-going training opportunities.

3. SECTION THREE
PRACTICE-BASED LEARNING

Higher education institution

3.1 The HEI tutor will liaise with the placement provider regarding arrangements for tutor support during the placement. Details of this support will be clearly stated and methods of communication made explicit.

3.2 Tailored HEI support will be provided as appropriate where the student and/or placement educator or placement provider requires additional support.

3.3 The HEI will establish audit procedures, which will maintain and develop quality placements.

3.25 The student will engage actively in learning, in order to develop his/her integration of theory to practice.

3.26 The student will take ongoing responsibility for developing skills of accurate self-reflection, evaluation and monitoring, throughout all placements.

3.27 The student will be responsible at all times for their own and their patients/ clients' health and safety within the placement and should not compromise the health and safety of the patients/clients.

3.28 The student will recognise that the needs of the patient/client will take priority at all times.

3.29 Where different models of placement exist, such as paired placements, the student will be aware of his/her responsibility to all parties, including student peers.

3.30 The student has a responsibility for alerting the placement educator and HEI of any factors negatively affecting his/her learning.

3.31 The student will take responsibility for alerting the placement educator, and/or placement provider and/or HEI if the agreed feedback and monitoring does not take place.

3.32 The student will take responsibility for being knowledgeable about the assessment process and criteria for the placement, and using that knowledge when seeking guidance on progress and self-reflecting.

3.33 The student will seek an “end of placement” review with his/her placement educator/s to review the learning and assess future learning needs.

4. SECTION FOUR
AFTER THE PLACEMENT

Higher education institution

4.1 The HEI will have a transparent, documented process of ‘post placement feedback’ in order that all partners involved in the student’s practice-based learning have an opportunity to reflect on what learning, if any, would be valuable in the future. This will involve the placement provider and placement educators.

4.2 Learning that emerges from post placement feedback will influence further training of placement educators and HEI tutors.

4.3 The HEI will give students the opportunity to be involved in reflective discussion and planning of their future practice–based learning.

4.4 The HEI will provide clear guidelines and procedures that placement provider, placement educator and student all follow when a student does not reach the required level of competence.

4.5 Each student who does not reach the required level of competence will be directly guided from the HEI on future action and options, with reference to university and course regulations and professional requirements.

4.6 The HEI has a responsibility to ensure that a student who fails a placement has an opportunity to seek guidance as to whether speech and language therapy is the profession of choice for them. The student will be clear that he/she has a choice to progress to a resit placement, if the regulations allow this.

4.7 A student who wishes to exit without a professional award will have his/her choice respected and will be supported in this.

5. SECTION FIVE
LEARNING RESOURCES TO SUPPORT PLACEMENT

Higher education institution

5.1 Applicants to speech and language therapy courses will be informed of any travel and financial implications of practice-based learning, in advance of accepting an offer.

5.2 The HEI will ensure that the student is aware of the financial support available for attending placement.

5.3 All HEI placement tutors will be registered with the HPC and should hold certified membership of the RCSLT.

5.4 There will be adequate access to, and support from HEI staff, library, placement resources and materials, while the student is on placement, although it is recognised that logistic constraints will exist.

6. SECTION SIX
QUALITY MONITORING, MANAGEMENT AND ENHANCEMENT

6.1 All partners will comply with quality monitoring processes and procedures within their own organisations, with a view to both the audit and enhancement of practice-based learning.

6.2 The outcomes from all quality monitoring and enhancement processes and procedures focussing on practice-based learning will be made available to all partners.

6.3 HEIs will inform students through their course-level or university-level documentation of the appeals, grievance, and complaints procedures, in respect of practice-based learning.

Where the student has to resit a placement:

6.4 The HEI will make explicit the type, length and regulations governing a resit placement to students, placement providers and placement educators.

6.5 The placement provider and placement educators will be informed if a placement is a resit placement.



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APPENDIX 1

Methodology

The RCSLT Education and Workforce Development Board established a working group. The group included a newly-qualified speech and language therapist, experienced placement coordinators from HEIs, and experienced placement providers and placement educators, reflecting the four countries.

The standards were developed using all available sources of current and best practice as captured in HEI, RCSLT, HPC, QAA and NHS documentation. A working framework was developed. The sources were reviewed, analysed and coded, which resulted in the extraction of common standards. The framework was then refined in light of the common standards.

A student study day, held by RCSLT in February 2005, allowed for the collation of student views as to what should be included in national standards for practice-based learning. A forum was held in May 2005, where the resulting feedback produced a penultimate draft of the Standards. Following a consultation phase and subsequent modifications, a final draft was circulated once more for consultation. The resulting final document was then agreed by the Education and Workforce Development Board and sent to Council for approval in December 2005.

APPENDIX 2

Context

The RCSLT competencies frameworks relate to three layers of professional practice – the tasks, the process, and professional judgement and decision-making. This maps clearly to the QAA Benchmark statement.

The Benchmark statement for speech and language therapy states that: *a student's profile takes into account the following three skills and abilities.*

- *Ability to understand, critically evaluate and apply relevant theoretical knowledge to clinical practice;*
- *Technical skills such as the manipulation of assessment and therapy tools, materials and the environment;*
- *Interpersonal and communication abilities, used to set up and maintain a therapeutic atmosphere, where patients/clients are facilitated in an optimum communication environment.*

The introduction to the HPC Standards of Proficiency (SOP) states that *although students may only have practised 'under supervision and not independently,' they must be confident that they can meet the standards of proficiency when they work without supervision. The SOPs are structured around standards of:*

1. *Expectations of a speech and language therapist*

    - *Professional autonomy and accountability*
    - *Professional relationships*

2. *Skills required for the application of practice*

    - *Identification and assessment of health and social care needs*
    - *Formulation and delivery of plans and strategies for meeting health and social care needs*
    - *Critical evaluation of the impact of, or response to, the registrant's actions*

3. Knowledge, understanding and skills for speech and language therapy

It follows therefore that practice-based learning in speech and language therapy should develop skills and abilities in line with the standards stated in the QAA Benchmark and HPC SOPs and articulate with the RCSLT competencies frameworks.

The work on *Communicating Quality 3* should also adopt these RCSLT Standards for Practice-based Learning, providing coherent, integrated professional body guidance on good practice.

Appendix 3

Reading List

Bray, M., Ross, A., Todd, C. (1999) Speech and Language: Clinical Process and Practice (New edition in press)

Brumfitt, S. (2004) Innovations in Professional Education for Speech and Language Therapy. London: Whurr

Hegde, M.N., Davis, D. (1999) Clinical methods and practicum in speech-language pathology. 3rd ed. San Diego, Calif.: Singular Pub. Group.

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McAllister, L., Lincoln, M. (2004) Clinical education in speech - language pathology. London: Whurr.

Van der Gaag, A. (1996) Communicating Quality 3: Professional Standards for Speech and Language Therapists.

Williams, D. (2002) Writing Skills in Practice: A Practical Guide for Health Professionals. Kingsley.

Video: Teaching and Learning in a Clinical Setting. A guide for students and supervising clinicians. Sheffield University Television.

Appendix 4

Acknowledgements

EDUCATION & WORKFORCE DEVELOPMENT BOARD

RCSLT National Standards for Practice-based Learning Working Group

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Teresa Boden, SLT Manager (Paediatrics), Portsmouth City Teaching PCT
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*Steering Group members

ROYAL COLLEGE OF SPEECH & LANGUAGE THERAPISTS

Position Paper

Inclusive Communication and the Role of Speech and Language Therapy

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1.Introduction

Communication is central to our ability to learn, work, form and maintain relationships and to participate in society. Across all aspects of life, in education, care and enablement, huge demands are placed on our communication skills and this impacts everyone.

Everyone needs to be able to communicate to participate effectively in daily life. Recent policies across the four nations of the United Kingdom (UK) expect services and organisations to co-produce and engage with people who use their services. This requires reasonable adjustments to communication, to reduce barriers and inequality.

Speech and language therapists (SLTs) are key players in promoting communication inclusion. It is embedded firmly in some specialisms. However it is equally relevant across all speech and language therapy services. This position paper sets out the Royal College of Speech and Language Therapist's (RCSLT's) expectation that inclusive communication is integral to all SLTs' work in the future. It highlights the need for a consistent understanding and use of the term and to promote inclusive communication for all. It outlines roles for all SLTs, from working together with individuals through to working across communities and populations. It describes the need for SLTs to be involved with inclusive communication - in practice, audit, evaluation and research.

2. Purpose and benefits

This inclusive communication position paper is aimed at SLTs and the purpose of the paper is to:

1. Describe the need for SLTs to promote and practice inclusive communication and the risks of not doing this
2. Set out a definition of inclusive communication that can be used consistently by SLTs
3. Develop a shared understanding of terminology
4. Raise awareness and align previous strategic work on inclusive communication across the UK
5. Act as a guide for good inclusive communication practice
6. Outline the multi-level roles of SLTs in developing and implementing inclusive communication approaches
7. Recommend methods for evaluating, sharing and developing good practice in inclusive communication

The benefits of this position paper for the speech and language profession and individual SLTs are to:

- Provide personal and professional credibility for SLTs improving inclusive communication at all levels of practice
- Enable SLTs to feel confident about the quality of the advice they are giving and feel supported by professional consensus
- Ensure a consistent quality of inclusive communication speech and language therapy practice, providing a direct benefit to service users, communication partners and commissioners
- Create a baseline for evaluation, audit and research, to compare the impact of different approaches at different levels with a view to shaping future inclusive communication practice across the UK
- Increase efficiency by sharing already established inclusive communication standards and removing the need for SLTs to reinvent local standards
- Support SLTs to make a strong case (including reduction of risk) for inclusive communication activity at service and population level

3. Methodology

3.1 Working group

The RCSLT put a call out for volunteers to sit on a working group early in March 2013 and the group first met in May 2013. This was in response to increasing requests from RCSLT members for some formal guidelines to direct inclusive communication practice among speech and language therapy professionals.

A number of clinical areas of speech and language therapy and all four UK nations were represented in the working group.

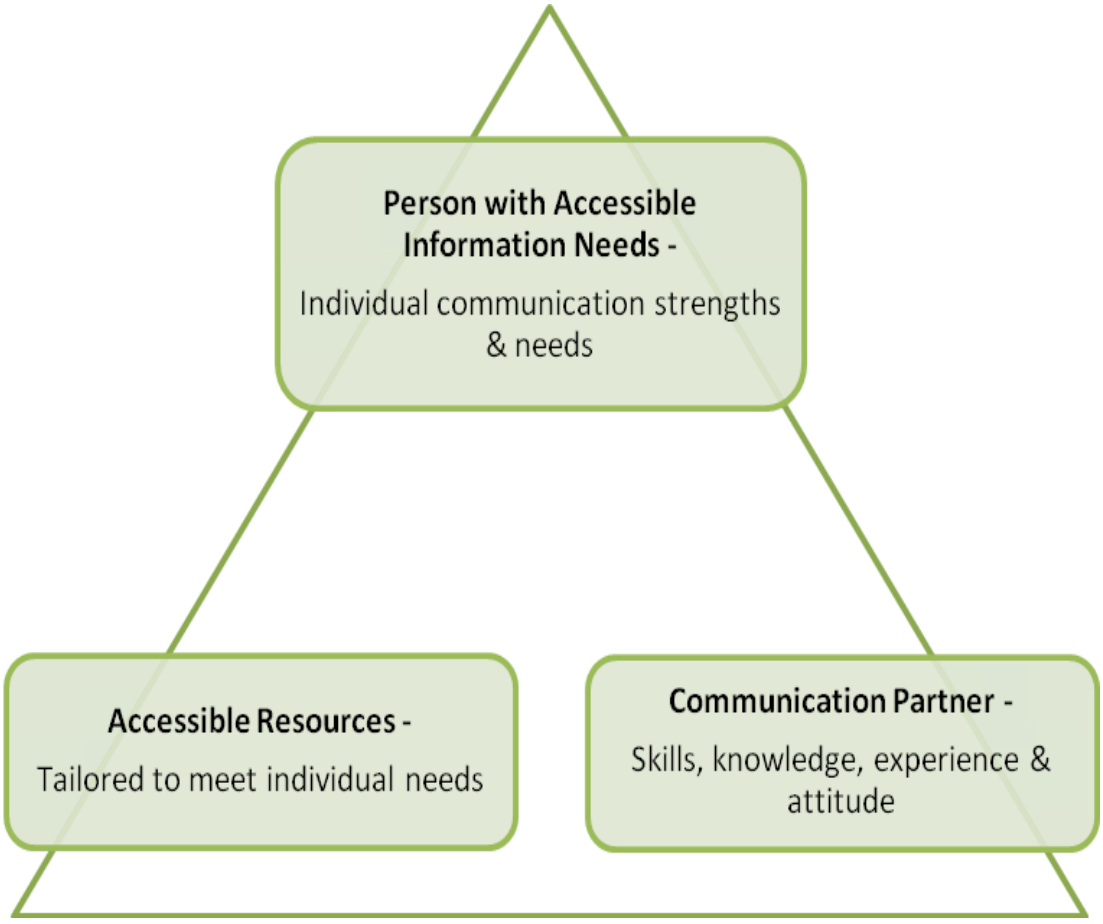
3.2 Literature search

There is limited primary research into inclusive communication practice. Mander (2013) carried out a detailed review of the literature within the field of learning disabilities and found seven relevant primary research studies. However these studies focused on communication resources rather than the impact of inclusive communication practice on people with communication needs. Three mixed method studies described a qualitative process of developing and/or appraising a specific accessible resource or guidelines as well as a quantitative element to investigate its effectiveness (Strydom et al, 2001; Rodgers and Namaganda, 2005; Boyden et al, 2009). Two qualitative studies attempted to answer broader questions relating to the human dimensions and experiences of accessible information. One explored the use of accessible information with a wider population (Owens, 2006) and the other explored issues relating to the implementation of a specific accessible resource (Jones et al, 2007).

Results were similar across different specialisms. Several researchers have identified themes or processes that need to be considered to improve accessibility. Howe (2008) identified seven environmental act barriers or facilitators for people with aphasia: (1) awareness of aphasia; (2) opportunity for participation; (3) familiarity; (4) extra support for communication; (5) communication complexity; (6) message clarity; and (7) time available for communication. O'Halloran et al (2012) also identified seven themes that promote accessibility, relating to the healthcare provider's knowledge, communication skills, attitudes and individual characteristics, together with the presence of family, the physical environment, and hospital systems. They concluded that removing barriers and maintaining factors that facilitate communication may contribute towards communicatively accessible stroke units.

These studies demonstrate that the challenge of providing information is more complex than the provision of accessible information. It involves the whole process - respecting people as individuals and finding ways of making SLTs responsive and sensitive to what people with high communication needs 'tell' them (Thurman et al, 2005). Inclusive communication is about reducing barriers to communication, for everybody, everywhere. It therefore focuses on the process of making communication inclusive or accessible. For many this requires individualised approaches and specific support, as illustrated by the Triangle of Accessibility (fig.1) below (Mander, 2009). The Triangle of Accessibility clearly demonstrates that inclusive communication is a process requiring targeted, individualised resources together with appropriate communication partners.

Figure 1: The Triangle of Accessibility



Communication partners can access various learning and development resources to support their inclusive communication skills and knowledge. These range from workshops and courses to guidance around how to develop and use written accessible resources. Examples of guidance include, amongst many, Mencap – Am I

making myself clear (2009) and the Stroke Association – Making information accessible for people with aphasia (2012). Mander (2015) found a shift towards seeing information as a process of supporting understanding and comprehension needs.

The working group for this position paper identified a gap in the evidence around processes communication partners use, the outcomes and the impact of inclusive communication practice. To meet this gap, the working group developed a two-part survey for RCSLT members to build clinical evidence and expertise around inclusive communication processes, outcomes and impact. This expert consensus informed the position paper and then underwent a further process of member consultation.

3.3 Member survey

The inclusive communication member survey was an online survey distributed across the RCSLT membership. The survey was divided into two parts. The first part, completed by 254 members, was aimed at defining and reaching a consensus on what inclusive communication means and capturing a record of what inclusive communication work SLTs are involved in.

The second part, more qualitative, was targeted at those who completed the first survey and had agreed to further contribution. It was completed by 102 SLTs who are involved in inclusive communication work. This second part focused on the models of inclusive communication practice, evidence, benefits and effectiveness.

3.4 Writing of the guidelines

In May 2013, the initial working group set out a plan to develop the paper, a process which took three years to complete.

Initially the members of the working group were allocated sections and individual tasks, such as the development and analysis of the member survey. Although coordinated by the nominated person, the group made decisions collaboratively through the process.

Following the consultation (see below), the working group discussed the findings which informed the purpose, structure and content of the final paper. The final paper was completed by a small group of RCSLT members. Following discussions between working group members, the paper went through several drafts for consultation.

3.5 Member consultation

The profession was alerted to the position paper being in development and was subsequently invited to review the document and make comments.

The draft was made available to appropriate RCSLT members; relevant clinical excellence networks, hubs, RCSLT board members and staff. Forty-four responses were received from the four UK nations. All submitted comments were discussed, approved or rejected, tracked and stored. The paper was re-drafted as appropriate.

The purpose and benefits of this position paper are specifically for the speech and language therapy profession (see chapter 2). Therefore there were no external consultations on the paper and no consultations with service users. Additionally the working group was mindful of the principles of inclusive communication which is not just a resource approach but a tailored process of inclusion. It is envisaged that, once published as a position paper, SLTs will share understanding and awareness around terminology, needs and roles and use appropriate processes of co-production and involvement.

4. Making the case for inclusive communication

4.1 Who benefits from inclusive communication?

Everyone needs to be able to communicate to participate effectively in daily life. Effective communication allows us to live independently, build and maintain relationships, to work, to be educated, to manage our affairs and, of critical importance, to assert our own free will in the world. Communication underpins the outcomes that individuals and governments value. Without effective communication it is very difficult to participate in the world around us.

The ultimate aim of inclusive communication is to reduce communication barriers, and subsequent prejudice and exclusion of and from society. The social model of disability sees disability as created by social barriers rather than individual impairment (Walmsley, 2001). It is these social barriers that are the ultimate factors defining who is disabled and who is not. Inclusive communication supports all members of society to be equal by reducing communication barriers for all people with communication difficulties.

Most people experience communication challenges at some point because of illness, or stress and anxiety associated with challenging situations, for example, when they are in unfamiliar surroundings or doing an unfamiliar task. For people in the UK with speech, language and communication difficulties, communication challenges are a regular experience. For them, inclusive communication is paramount.

Speech, language and communication difficulties create inequality and can arise at any time across the lifespan and anywhere. Optimum communication for individuals in places where they live and work reduces the risks of exclusion, inequality and poor health and wellbeing associated with disability. Optimum communication promotes more effective education, health, social care and access to justice, through more successful understanding, discussion and negotiation.

Inclusive communication requires a commitment and the ability to support people both at vulnerable times and throughout their lives. Reasonable adjustments to meet everybody’s inclusive communication support needs are a step towards better outcomes for all individuals and the wider community, enabling greater independence and participation.

SLTs are key players in promoting communication inclusion and as such can make a substantial contribution to important policy goals such as increasing health

literacy, promoting person-centered care, public health and health inequality initiatives.

Inclusive communication is embedded firmly in some speech and language therapy specialisms. For example, in services for people with learning disabilities or with aphasia, SLTs are supporting people to use their natural or retained communication strengths through inclusive communication strategies, to address barriers within specific contexts, such as using a chart in a café (see RCSLT inclusive communication webpage for further examples). Many learning disability and stroke multi-disciplinary teams (MDTs) expect to work as partners with SLTs on inclusive communication.

Inclusive communication however is relevant across all speech and language therapy services. In fact it is not just about best practice within the field of speech and language therapy. Inclusive communication is set within a legal framework and it is RCSLT's expectation that inclusive communication is integral to all SLTs.

4.2 Making the case

4.2.1 The economic case

Inclusive communication improves the likelihood that people will be able to access the right service at the right time, and benefit from that service first time, every time. Implementation of quality inclusive communication practice therefore has a high potential to save money and time for individuals, communities and countries.

Being socially included and connected with access to employment, education, health, social care, justice and culture are primary factors for protecting and promoting an individual's health and wellbeing, and for creating fair, safe and prosperous communities. Communication underpins these factors; conversely, communication barriers are high-risk factors for poor health and wellbeing, community cohesion and the public purse.

The Scottish Government commissioned a review of the literature (Law et al, 2007) on the lived experience of people with communication support needs, and reported that in comparison with the general population, people with communication support needs are more likely to:

- experience negative communication within education, healthcare, the criminal justice system and other public services;
- have difficulty accessing information required in order to utilise services;
- be misjudged in terms of cognitive and educational level;
- be unemployed or employed at an inappropriately low level;
- live in socially deprived areas; and

- be victims of, or be convicted of, crime.

A study using data from a UK birth cohort of 17,196 children followed them from school entry to adulthood. The study found that, even after adjustment for a range of other factors, speech and language difficulties at age five are significantly associated with poor literacy, mental health and employment outcomes at age 34 (Law et al, 2009).

Outcomes for young people with identified communication support needs can be negative in the extreme. In relation to employment, a study of young, unemployed men found that more than 88% were described as presenting with language impairment, having some degree of difficulty with language (Elliott, 2011) with rates of 66-90% of young offenders with speech, language and communication needs (SLCN) reported (Bryan et al, 2007). In Polmont Young Offenders Institute, 26% of young men were found to have clinically significant communication impairment and 70% have difficulties with literacy and numeracy (Polmont, 2003). More recent studies in adult prisons and work by intermediaries (England, Wales, Northern Ireland) has added to the weight of evidence linking SLCN with involvement in the criminal justice system (as witness, victim and/or accused) (RCSLT, 2012).

4.2.2 The demographic case

The communication profile across all four nations is changing. People are living longer, including many with long-term conditions associated with communication difficulties; for example, children and young people with complex additional support needs, frail older people, and people living with Alzheimer's disease and other types of dementia. Future populations will include increasing numbers of people requiring more effective and universal communication support.

4.2.3 The policy case

National strategies and policies emphasise the need for services to be person-centred, rights- and asset-based, and developed using a co-production model. This requires universal inclusive communication approaches so individuals with speech, language and communication difficulties experience reduced inequalities, and have more positive experiences of safe and effective services across all the dimensions of health, social care, education and employment. Self-management and informed choice runs through policies and strategic direction requiring individuals to make and express an informed choice, whatever their communication strengths and weaknesses.

Services are required to evidence:

- **Empowerment:** a core pillar of the human rights based approach outlined in the Human Rights Acts Article 10 (1998) and Scottish National Action Plan on Human Rights.
- **Participation:** of people in decisions that affect them. There is a need for greater consistency to ensure meaningful participation of people in decisions that affect their lives.
- **Person-centred service provision:** requiring services to interact and communicate with actual and potential service users in ways that work for their service users.
- **Rights-based services:** applying equality and human rights laws.
- **Asset-based approaches:** using the assets of an individual and/or community to problem solve. This requires service providers to take an inclusive view.
- **Co-production:** requiring all parties to listen, to understand each other and to facilitate equal expressions of opinions and choices no matter their communication needs and abilities.

4.3 Risks of communication exclusion

Failure to make reasonable adjustments to meet communication needs will mean individuals will continue to be vulnerable to a range of risks (Five Good Communication Standards, RCSLT, 2013). These risks are caused by people misunderstanding or being misunderstood across all dimensions of education, treatment, social care, support and enablement.

Misunderstanding or being misunderstood leads to heightened probability of occurrence of risks, associated with:

- Health inequality (Locke et al, 2002), lower standards of healthcare, misdiagnosis, diagnostic overshadowing, taking medication wrongly or not effectively following health advice, inpatient admissions and inadequate treatment of serious medical conditions
- Poor health literacy, meaning individuals struggle to recognise, obtain, and understand basic health information which they need to make appropriate health decisions and to access the services which prevent or treat illness and enable them to self-manage their health and wellbeing (NHS Education for Scotland, 2014)
- Withdrawal and social isolation as inclusive communication is essential to building relationships, interacting and participating in family life, making friendships and being part of the wider community. These are all fundamental for citizenship and humanity and central to a good quality of life (Bercow, 2008)

- Poor mental wellbeing. Communication difficulties and negative experiences, across any dimension of care, enablement and support, can lead to low mood, anxiety and depression
- Increased vulnerability and a heightened risk of abuse (Sylvestre et al, 2015) and neglect, alongside hate crime
- Increased presentation of behaviours which challenge services, indicate mental distress or offend, leading to increased involvement with the criminal justice system (Bryan et al, 2007) or safeguarding incidents. Avoidance of these very costly outcomes depends on access to optimum communication support, understanding and therapeutic input, in a rapid and timely manner
- Legal challenges based on continuing failure to design, commission and provide best-practice services, in contravention of legal responsibilities and the demand for increased person-centredness and co-production of service design and delivery (Equality Act, 2010)
- Transitions, for example, the transition from childhood, illness, death of a carer, becoming a parent
- Lack of access to information required to use services, for example, social services or welfare services (Law et al, 2007)
- Reduced ability to engage in education and work (Elliot, 2009; Law et al, 2009). This leads to misjudgement in terms of cognitive and educational level, resulting in unemployment or people being employed at an inappropriately low level
- Reduced housing opportunities and welfare. This can lead to overuse of specialist services and 'out of area' placements
- A lack of person-centred approaches leading to reduced choices and involvement in everyday decisions, as well as participation in wider community and leisure opportunities
- Staff teams consistently overestimating an individual's abilities, impacting negatively on staff perceptions and affecting the individual's overall care (Law et al, 2007)

4.4 Current terminology

Prior to this position paper, various terminologies have been used interchangeably. The term inclusive communication is also referred to as good communication, total communication and accessible information. Some terms are synonymous and there is overlap between them all. There has been a lack of a shared definition of what both SLTs and others mean by these various terms (Lewer, 2009). Below are listed the terms associated with this field of practice and their respective common definitions.

4.4.1 Inclusive communication

Inclusive communication aims to make services more accessible for everyone. Most definitions of inclusive communication include statements about values, social inclusion and communication environments. The term encompasses all levels of practice: population (relating to everyone, everywhere); targeted (relating to high risk SLCN communities and services); and specialist (relating to specific individual needs). This term and definition is not new.

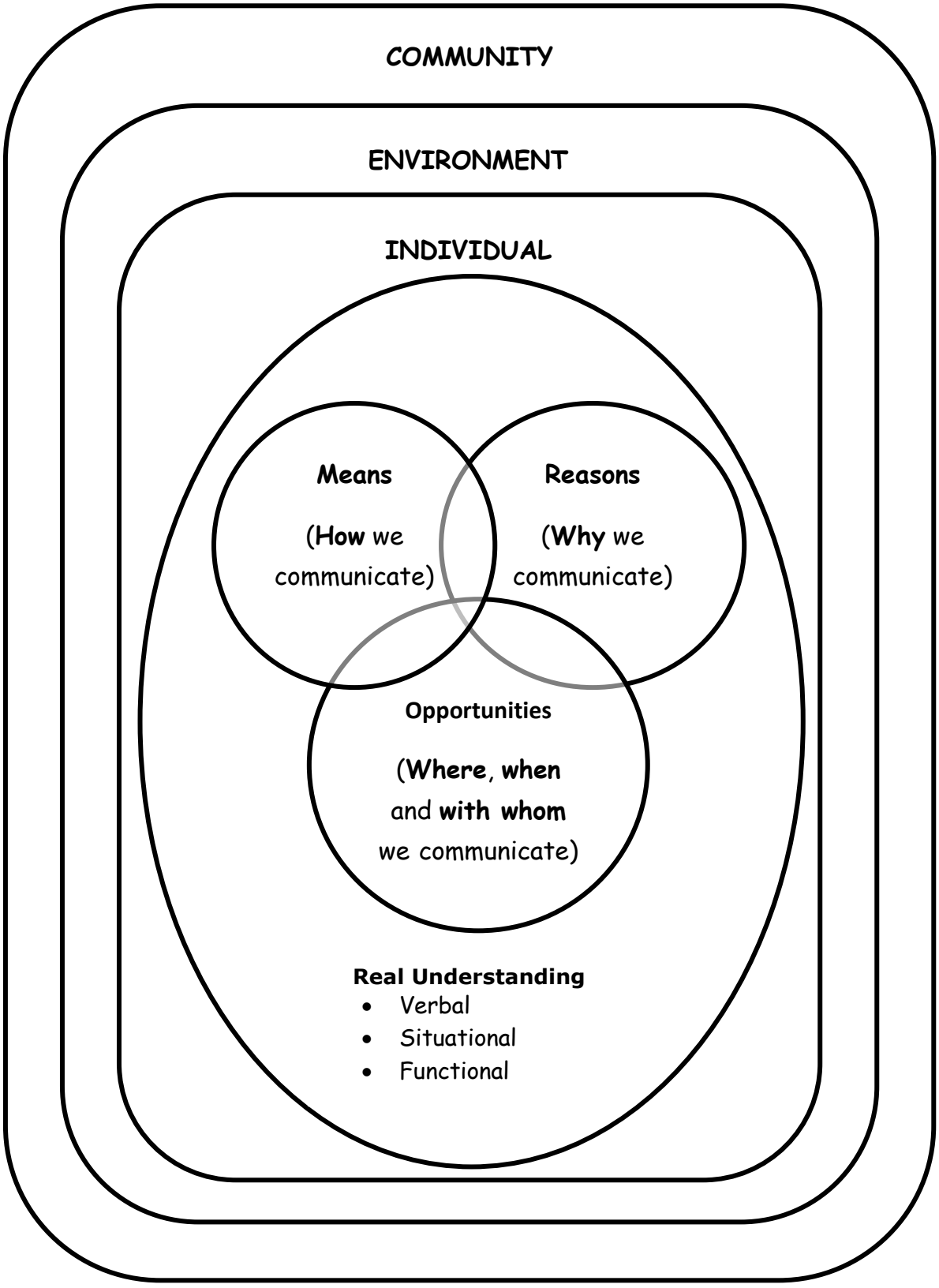
In Scotland, inclusive communication is an established term endorsed and used by the Scottish Government since 2009. The definition of inclusive communication from the co-produced Talk for Scotland Toolkit (Communication Forum Scotland, 2009) is: 'Inclusive communication makes use of the broadest range of methods to help people to understand and express themselves'.

The toolkit recommends use of all means by which human beings understand the world and express themselves. These are listed below in broadly simple to complex developmental order, concluding with reading and writing, the most complex means of understanding and expressing themselves:

- Routines
- Environmental sounds, smells, taste
- Facial expression
- Head and body language, eye pointing
- Place/location
- Objects
- Gesture
- Photographs
- Symbols and drawings
- Verbal language
- Signing
- Written word

Inclusive communication is not a new concept. Figure 2 (pg. 17) illustrates this tiered model of inclusive communication, published in 2002 by Money and Thurman, describing a model towards inclusive communication highlighting individual, environment and community levels.

Figure 2: A Model of Inclusive Communication (Money and Thurman, 2002)



The Scottish Government's (2011) definition of inclusive communication: 'Means sharing information in a way that everybody can understand. For service providers, it means making sure that you recognise that people understand and express themselves in different ways. For people who use services, it means getting information and expressing themselves in ways that meet their needs. Inclusive communication relates to all modes of communication: face to face, written information, online information and telephone' (pg.04).

Outside Scotland, the Inclusive Communication Network's 'Valuing communication, valuing lives: A model for communication passports' describes inclusive communication as an approach that: 'Seeks to create a supportive and effective communication environment, using every available means of communication to understand and be understood. Inclusive communication means using the right communication type at the right time based on an individual's needs' (MCN CCQ, 2013).

4.4.2 Total communication

Most definitions of total communication are person centred and tend to focus on an individual's needs first and then how the individual is supported within their community. There tends to be less focus on the universal application of strategies in these definitions. This definition is taken from the Total Communication website:

'Total communication is a process that ensures that all forms of verbal and non-verbal communication are recognised, valued and actively promoted within an individual's environment. Our aim is to ensure a 'common language' is adopted for all people to help make a consistent and positive difference to everybody's lives. The tools of total communication are gesture, body language, signing, facial expression, objects of reference, photographs, drawings, symbols, written words, vocalisation, intonation, verbalisation and access to modern technology. It is focussed on individuals and an awareness of and ability to use whatever is right for an individual – inclusive of all.'

A different definition of total communication is used in the education of hearing impaired children. In this instance the term total communication means formal signs with speech and writing, and sometimes Sign Supported English. British Sign Language signs are also usually included.

4.4.3 Accessible information

Accessible information means different things to different people. Accessible information is generally concerned with developing resources, making written information easier to understand for people who find reading hard, such as

people with learning disabilities or difficulties, dementia and aphasia. Different words are used to describe accessible information, for example:

- Easy read or easier read
- Aphasia-friendly information
- Making information easier
- Easier to understand information
- Simple words and pictures
- Easy write or easy info

Generally these terms mean using easy words (ie, used commonly in everyday interaction) and pictures (eg, symbols, cartoons and/or photographs), writing in short, simple sentences (ie, one point/sentence in the order people are expected to do, see, understand something) and without any abbreviations or professional jargon. There is not a legal definition of what easy read information must look like; however, a minimum standard for easy read information has been created in consultation with people who regularly make or commission easy read information (DH, 2009).

Accessible information approaches can focus on the process, not just the resource, considering individual's strengths and needs, the communication partner's skills, knowledge and experience and then tailoring the accessible information for a specific person (see fig. 1, Triangle of Accessibility, pg. 8). The term accessible information can now describe wider means and purpose of communication, beyond simply understanding printed or online visually mediated communication. In 2014, services in England adopted the Accessible Information Standard (see chapter 6). The Accessible Information Standard is not just about written information in different formats, but includes making sure that people get the support with communication that they need, such as interpreters, advocates, communication partners and communication tools, such as an aid or a communication passport, to help them both understand and express themselves.

4.5 Consensus around inclusive communication definition and terminology

The first part of the RCSLT member survey (section 3.3, pg. 9) sought to both define inclusive communication and develop a consensus opinion on terminology. The results confirmed that although members were positive about the term there was disagreement and/or confusion about definitions of inclusive communication. There appeared to be regional variation as well as differences between speech and language therapy specialisms. There also seemed to be overlap between the terms 'inclusive communication' and 'total communication',

with some respondents discussing the use of total communication strategies within a wider context of inclusive communication.

It is not beneficial to have a variety of terms in use. One broad term with one definition, used by RCSLT and its members, would create greater consistency and understanding - not just within the profession but also for our service users and service providers and commissioners. It would also enable clearer referencing within national policies and strategy.

RCSLT's Board of Trustees agreed that 'inclusive communication' is the preferred term of the organisation. A unified term and definition will lead to improved profile and identity for the term used and the speech and language therapy profession. It is an umbrella term that encompasses other terms that may be established in local use.

4.5.1 Defining inclusive communication

Inclusive communication encompasses all means of understanding and expression and all tools which enable and support communication. This includes strategies to overcome high level language difficulties, through to creative and multi-modal techniques to engage people with profound and multiple learning disabilities.

The RCSLT vision is for all individuals with SLCN – permanent or transient, formally identified or not – to experience and benefit from inclusive communication. It is a necessary foundation to achieving successful outcomes including independence and community participation.

Inclusive communication practice recognises that inclusion is not absolute for an individual with SLCN, and that what counts as inclusive for one person will not necessarily be so for someone else (Mander, 2013).

Inclusive communication practice means not solely focusing resources on the needs of relatively few individuals. It is also concerned with communication partners and their knowledge, skills and attitudes towards communication inclusion. Communication partners, in all their interactions, must be able to use strategies and resources effectively to enable communication inclusion for as many people as possible, to the greatest degree possible.

Inclusive communication is about both the identified and unidentified communication needs of the general population. Every community includes people with SLCN all the time. Therefore, to ensure equality, inclusive

communication approaches are required to benefit the entire population and society - inclusive communication for everyone, everywhere, all the time.

Inclusive communication practice therefore encompasses three different levels:

1. **Individual level** - ensuring individuals can use inclusive communication tools or methods to understand information and express themselves in ways that utilise their communication strengths and meet their communication needs. This means that:
    - Individuals get the professional and personal support needed to enable them to communicate to their full potential
    - Whatever communication methods (verbal or non-verbal) work best for an individual are used consistently by everyone communicating with the individual
    - Communication partners (family, friends, support workers and others) are fully involved in identifying what works best for individuals. They understand and value individuals' communication, listen and take time to support their communication and maximise involvement.

2. **Environments, organisational and service level** - ensuring that communication needs are no longer a barrier to access or inclusion in a place, service or organisation through consistent use of inclusive communication practice. This means that environments, services and organisations:
    - Have leaders who understand the economic, legal and policy arguments for quality-assured inclusive communication practice and promote~~s~~ and encourage~~s~~ a positive vision for and attitude towards inclusive communication best practice
    - Apply a shared, evidence-based definition of quality inclusive communication practice
    - Have joined up, comprehensive inclusive communication strategies in order to make the vision of a communication inclusive organisation a reality. Policies and strategies take into account the full range of communication abilities and needs of actual and potential populations accessing the service. Needs are planned for rather than responded to because every community or group may include people with communication support needs (Communication Forum Scotland, 2010; RCSLT, 2013)
    - Ensure sustained and sustainable investment of both time and money to ensure effective implementation of the inclusive communication strategy. Quality communication tools, approaches, training and technology are freely available without professional, financial or commercial barriers

- Integrate inclusive communication strategies, as standard, in to all communications/interactions between service provider and actual potential users. Communications include all signage; such as face-to-face interactions (from receptionist onwards), printed materials, leaflets, forms, online communication, phone services, focus groups and conferences
- Provide comprehensive learning and development programmes for communication partners to enable effective implementation of inclusive communication
- Have a means of regulating, monitoring, evaluating and continuously improving inclusive communication practice

3. **Community or population level -** ensuring comprehensive, coherent implementation of policy and practice standards which takes into account the diverse communication strengths and needs of whole communities and populations. This means that:
   - There is widespread understanding of the economic, legal and policy arguments for quality-assured inclusive communication practice among national and local government leaders and key stakeholders
   - Local and national government have and 'own' a shared vision for and of an inclusive communication nation
   - Local and national government apply a shared, evidence-based definition of quality inclusive communication practice, including quality standards and indicators of these standards
   - Local and national government:
     - have a joined up, comprehensive national inclusive communication strategy to deliver their shared vision
     - provide sustained and sustainable investment of both time and money to ensure effective implementation of the inclusive communication strategy
     - demonstrate best inclusive communication practice throughout services
     - have a means of regulating, monitoring, evaluating and continuously improving inclusive communication practice

5. Legislation and policy

Position papers seek to capture the most up-to-date evidence base and best practice principles for a given clinical area. This will be common to all parts of the UK, and indeed beyond. But the context for delivering services in that clinical area may vary between England, Scotland, Wales and Northern Ireland due to legislative, regulatory, national and local policy differences.

To ensure that a position paper has a longer shelf-life, an up-to-date summary of relevant laws, regulations, policies and guidance can be accessed on the RCSLT inclusive communication webpage. This ensures that position statements are relevant to the whole of the UK, and the context can be updated as soon as it changes. Where it is unavoidable, relevant documents have been referenced within the main text (always for all four nations). Local context should also be researched when considering taking forward recommendations from a position paper.

European and UK-wide legislation supports inclusive communication. It is not just about best practice within the field of speech and language therapy. Various laws across the four UK nations covering equality, rights and capacity set inclusive communication within a legal framework. All these highlight the need for practicable steps to be taken to support individual communication needs, are fundamental for treating individuals with compassion and dignity and providing person-centred care.

6. Inclusive communication standards and principles

6.1 Five Good Communication Standards (UK-wide)

Following the Winterbourne View scandal, it was clear that patients with learning disabilities and/or autism in hospital settings were at risk because of poor communication. This was not just at an individual level, but also at the level of services and organisations that they used. Communication breakdown was clearly an environmental risk factor as staff were not generally interacting with the people they supported in a way that enabled individuals to achieve greater levels of independence, participation or integration (Mansell, 2007). This indicated the need to develop the communication environment and the RCSLT (2013) recommended Five Good Communication Standards around reasonable adjustments to maximise engagement, involvement and inclusion at an individual and service level. Requested and supported by the UK government, and endorsed by the then named RCSLT Council, the five standards are universally applicable across the life span and conditions.

The Five Good Communication Standards:

1. There is a detailed description of how best to communicate with individuals
2. Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services
3. Staff value and use competently the best approaches to communication with each individual they support
4. Services create opportunities, relationships and environments that make individuals want to communicate
5. Individuals are supported to understand and express their needs in relation to their health and wellbeing

The Five Good Communication Standards are intended as a practical resource to support families, carers, staff, professionals, providers and commissioners to make a difference to the lives of individuals. As a result of these standards, all stakeholders should know:

- What good communication looks like
- Whether good communication is happening
- About useful resources to promote good communication

The Five Good Communication Standards aim to support individuals to make and understand choices, express feelings and needs, and involve themselves in the world around them. The support needed will vary from person to person

but the implementation of the standards should mean individuals are able to say or experience (Thurman, 2009):

- Whatever communication methods work best for me are used and valued
- People communicate effectively with me because of their underpinning knowledge, skills and attitude
- People actively listen to me and take time to support my communication
- I get the professional support I need to communicate to my full potential
- The communication tools, techniques or technology I need are freely available to me
- Policies and strategies that affect me take into account my communication and include me in appropriate ways

The Five Good Communication Standards are increasingly cross referenced by key publications and embraced across wider learning disability services and broader specialisms. The Five Standards are relevant for a wide audience, underpinned by inclusive communication, and have been reframed as below to easily be adapted for different populations (Money, 2015; RCSLT Bulletin, October):

1. There is good information that tells you how best to communicate with someone
2. People are helped to be involved in making decisions about their care and support
3. Others are good at supporting someone with their communication
4. People have lots of chances to communicate
5. People are helped to understand and communicate about their health

6.2 Communication Support Principles and Principles of Inclusive Communication (Scotland)

The principles of inclusive communication were developed in Scotland, following a Scottish Government literature review of the lived experience of people with communication support needs (campaigned for and supported by RCSLT as a member of Communication Forum Scotland (CFS)).

The Scottish Government commissioned CFS to carry out the Civic Participation Network Project for people with Communication Support Needs. The four-year project (2010-2014) included co-production of the Talk for Scotland Toolkit, which sets out 6 Communication Support Principles, designed to facilitate effective communication between service providers and people living with communication support needs – regardless of why someone has a communication support need.

The Principles operate at the organisational/service and population level – covering all care groups and all environments, communication modalities and communication partners. The Talk for Scotland toolkit provides practical tools and guidance to support organisations – including government – to implement these principles. The toolkit was promoted through co-produced training across Scotland.

Still referred to regularly in Scotland, the 6 Communication Support Principles recommend that service providers:

1. Recognise that every community or group may include people with communication support needs
2. Find out what support is required
3. Match the way they communicate to the ways people understand
4. Respond sensitively to all the ways an individual uses to express themselves
5. Give people the opportunity to communicate to the best of their abilities
6. Keep trying

Following a change of personnel in the Scottish Government, the decision was made to publish the Principles of Inclusive Communication document. Informed by leaders of the Civic Participation Network Project these reflect the previously promoted 6 Communication Support Principles. The principles are accompanied by performance indicators to ensure communication is more inclusive within public authorities in Scotland.

Like the 6 Communication Principles, the Principles of Inclusive Communication were designed to cover all care groups and all environments, communication modalities and communication partners. They recognise people need similar communication supports wherever they are communicating. Their personal communication capacities don’t change as they move between environments and communication partners but the barriers they experience are dependent on the supports available in any given environment, or provided by any given communication partner.

The Principles were also actively co-promoted across agencies in Scotland and continue to be used and referred to by the Scottish Government and underpin ongoing inclusive communication projects, these principles are:

1. Communication accessibility and physical accessibility are equally important
2. Every community or group will include people with different communication support needs

3. Communication is a two-way process of understanding others and expressing yourself
4. Be flexible in the way your service is provided
5. Effective user involvement will include the participation of people with different communication support needs
6. Keep trying

The Principles of Inclusive Communication have continued to be promoted by the Scottish Government and subsequent commissioned national projects.

An examination of the implementation of inclusive communication practice was reported in a Scottish Government commissioned report 'The Joe Report: Making Scotland an Inclusive Communication Nation for him and for everyone else' (2011).

Although The Principles of Inclusive Communication were valued by both national and local government, the report identified simply having principles (or standards) is not enough. Assets required to comprehensively mainstream inclusive communication practice throughout public services included ownership and leadership by organisational senior staff; shared, evidence-based definitions of quality inclusive communication practice; realistic and sustained investment and a means of regulating inclusive communication practice. RCSLT, along with people with communication support needs and partner organisations, have made campaigning to establish an inclusive communication nation a strategic priority (2015-18). See also the RCSLT inclusive communication webpages.

6.3 Accessible Information Standard (England)

Since July 2016 all organisations providing NHS or adult social care in England follow the Accessible Information Standard: 'The aim of the standard is to make sure that people who have a disability, impairment or sensory loss get information that they can access and understand, and any communication support that they need' (NHS England, 2015). This includes making sure that people get information in different formats if they require, but also making sure that people get any support they need to express themselves; such as interpreters, advocates or other communication partners (NHS England, 2015).

Whilst targeted at the individual level it mobilises wide-scale systemic change across organisations that provide health and social care. It is not just about providing patient leaflets and letters in different formats such as large print, braille, via e-mail, in an audio format or in easy read. It also includes supporting people to communicate through using a hearing aid, lip-reading, or using a communication tool such as an aid or a communication passport. Notably it

covers arranging communication support for appointments, overnight stays in hospital, and for long-term care in care homes. It recognises that many people who benefit from accessible information will require additional support with communication through use of broader strategies.

The Accessible Information Standard requires all health and social care services to do five things:

1. Ask people if they have any information or communication needs, and find out how to meet their needs
2. Record those needs clearly and in a set way
3. Highlight or flag the person's file or notes so it is clear that they have information or communication needs and how to meet those needs
4. Share information about people's information and communication needs with other providers of NHS and adult social care, when they have consent or permission to do so
5. Take steps to ensure that people receive information which they can access and understand, and receive communication support if they need it

7. The role of the SLT

7.1 Why inclusive communication is relevant to all SLTs

Inclusive communication is everyone's role. However, SLTs have unique knowledge and skills to develop awareness, knowledge and understanding in others in order to maximise inclusive communication in all areas.

SLTs have a unique core theoretical knowledge of speech, language and communication. They bring specialist clinical skills focused on optimising an individual's communication capacity and improving quality of life. SLTs apply the social model of intervention to communication disability. They are well equipped to enable the best possible understanding between people with communication disabilities and their families, carers, staff and the wider community.

As such, SLTs are key players in leading and developing inclusive communication practice (in partnership with others) for individuals, environments, services, organisations, communities and populations. However, capacity, demand and commissioning will influence how much time SLTs can spend fulfilling their roles at these levels. This will be different between nations, localities, providers and specialisms.

The RCSLT inclusive communication survey in 2013 asked members about their inclusive communication practice and 95.3% of SLTs, out of 254 respondents, stated that their current role included inclusive communication work. The survey provided much information about the myriad of activities SLTs are undertaking at different levels related to implementation of inclusive communication practice. As predicted, roles and practice vary and examples of practice can be found on the RCSLT inclusive communication case studies webpage. The respondents reported that:

- 41.5% (n=105) worked with inclusive communication across all levels
- 58.5% (n=149) worked solely at the individual level
- More than three quarters stated their inclusive communication activity included learning and development, making resources and adapting environments
- 15% (n=38) had established inclusive communication standards in place with more than two thirds having none

7.2 Speech and language therapy roles at individual level

The credibility and value of speech and language therapy depends on its commitment to and ability to help people at the most vulnerable times of their lives. Regardless of age or clinical pathway, all SLTs bring unique expertise in assessing and describing an individual's preferred means of understanding, expressing themselves and interacting. This expertise has the primary aim of helping both the person and those around them develop the most meaningful communication – so that an individual's experience, needs and wants are better understood. This in turn enables service providers to communicate their messages and open up options and opportunities effectively for the individual.

At an individual level speech and language therapy services are engaged in person centered and individualised support of communication. To communicate effectively, it is essential that everyone understands and values an individual's speech, language and communication strengths and needs. Individuals should be supported and involved, together with the people who know them best, to develop a rich understanding of the best ways to interact together. SLTs facilitate development of this rich understanding and enable people to implement the best interaction strategies.

SLTs are key professionals, providing inclusive communication interventions, preventing health inequalities for individuals. People with SLCN may not be able to express discomfort or pain in a way that others understand or recognise. Therefore, information about the individual should include details of how the person communicates pain and distress, and people need to be trained to use this information and react appropriately. Staff also need to be aware of potential health risks and relevant referral pathways.

Individuals with SLCN are often either excluded from patient experience feedback processes or included in a tokenistic way. There is a risk that their needs and opinions are assumed, misinterpreted or ignored. For individuals, this will be improved if they receive information and are supported to express themselves in ways that meet their needs. All evaluation methods at the individual level will require inclusive feedback techniques for example; easy read questionnaires, Talking Mat approaches and one-to-one communication support (Mander and Rigby, 2014).

Speech and language therapy roles at an individual level include:

- Assessment of individual communication needs and strengths/assets
- Formulation and planning of interventions

- Specific communication interventions including description of communication strengths (typically 'communication profiles') and design and provision of individualised communication support strategies and resources
- Training, advice, mentoring and supervision of staff/co-working or supervising MDT colleagues to address the communication needs of individuals, ie, to enable them to implement strategies known to minimise communication difficulties and optimise and build on an individual's communication strengths/assets
- Evaluation and research
- Developing resources

7.3 Speech and language therapy roles at environment, service and organisational level

Inclusive communication seeks to create a supportive and effective communication environment, using every available means of communication to enable individual users to understand and be understood. Services and organisations need to demonstrate how they are supporting the inclusion and involvement of people with SLCN through use of innovative and creative solutions to communication differences.

SLTs are the key professionals to develop awareness, knowledge and skills in others in order to maximise communication. Where levels of risk and complexity are lower, direct speech and language therapy involvement may not be required, however speech and language therapy should be available to contribute to training and ongoing support and consultation to others. Others need to know when and how to access speech and language therapy support and resources.

Inclusive communication depends on services and organisations recognising that staff with a positive attitude, and the knowledge and skills to adapt their communication levels, styles and methods, is key. Staff should be aware of factors that impact on communication: sight, sensory integration, comprehension and expressive language abilities, and especially hearing. They need to know how to make reasonable adjustments to their communication, recognising that people understand and express themselves in different ways.

Staff need to understand that what they say and how they say it matters, and can impact positively or negatively on an individual's health and wellbeing in the short, medium and long term. Staff also need to understand how good communication underpins informed consent and capacity, as well as the broader benefits of inclusive communication.

Speech and language therapy services need to understand the inclusive communication needs of their local services and organisations, and enable them to achieve local standards, policies and strategies. SLTs should be available to contribute to the learning and development of multi-disciplinary, cross agency and cross sector colleagues, as well as educators, employers, carers and others who might interact with individuals with SLCN.

Additionally, speech and language therapy services have a responsibility to model good inclusive communication practice to other services and organisations by demonstrating good inclusive communication practice across every aspect of their own service – from working with individuals to speech and language therapy service planning and enabling access to speech and language therapy.

Speech and language therapy roles at environment, organisational or service level include:

- Assessing or auditing communication environments to identify attitudes, knowledge, skills and resources, strengths and needs
- Supporting development of positive inclusive communication environments, including supervision and training in application of appropriate communication strategies and resources for specific environments or services (ie, homes, schools, hospitals, prisons, day residential and nursing services)
- Supporting access to speech and language therapy services where appropriate
- Enabling services and organisations to make reasonable adjustments to communication to improve access to services
- Working with public health colleagues to improve access to health promotion materials

7.4 Speech and language therapy roles at population or community level

SLTs need to work together with local and national government, service providers, commissioners, key stakeholder and all public organisations to develop their understanding and ownership of inclusive communication. There is a role for influencing commissioning, contracting and staff development across agencies to raise issues around reasonable adjustments for people with communication disabilities. Organisations then need to demonstrate a commitment to inclusive communication at a strategic level, by anticipating that people with SLCN will be service users and therefore having inclusive communication strategies in place.

Clear reasonable adjustments must be described so people know what they can expect, services/providers know what adjustments they need to make, and commissioners and regulators know what they need to look for. Policies, strategies and standards are essential for sustainability and need to be woven into local, regional and national commissioning guidance.

Speech and language therapy services have a role in ensuring inclusive communication principles are embedded, not only in all aspects of their own service but also more widely at the level of large organisations and sectors (for example, Clinical Commissioning Groups (CCGs), health boards, public health services, education, culture, justice services) and whole communities - to ensure individuals get the support they need to communicate wherever and whenever they want to. This reflects both the social model of disability and underpins principles of independent living advocated by people with disabilities.

Work with individuals can help build inclusive communication capability in others, but for sustainability there is a need to build the capacity and capability for better inclusive communication across the health, education and social care and all other public services. A useful tool for building this capability could be setting standards within inclusive communication. The inclusive communication standards and principles described in chapter 6 are a good starting point for standards.

Speech and language therapy roles at population or community level include:

- Developing standards of good practice and guidance to achieving these at organisational, local community and national levels
- Leadership and support for national and local inclusive communication strategy development and implementation, advice and support to local and national government, services and commissioners on engaging and involving individuals with communication support needs
- Advising services on how to make reasonable adjustments to communication for individuals
- Developing and providing a range of learning opportunities in relation to communication, including multi-modal rolling training programmes at local, regional and national levels
- Supporting national and local organisations to develop more inclusive information, providing resources and skills to enable others to adapt information to meet the needs of people with communication needs
- Supporting organisational change/development programmes designed to mainstream inclusive communication approaches throughout organisations
- Communications with people for whom the service is being provided or

might be provided

For further examples across all three levels please see the inclusive communication webpage.

8. Evaluating the impact of inclusive communication

National drivers and outcomes set out in law may vary across countries and specialisms but ultimate outcomes for an individual with communication needs will generally centre on respect, safety, involvement, capacity, healthier lifestyles and reasonable adjustments, independent living, health and wellbeing outcomes (for example, Rights and Equality Based Outcomes for Learning Disability Services, Professional Learning Disability Senate 2016). These are outcomes for all professionals, services and organisations to work towards.

Inclusive communication is a step towards this ultimate outcome. It is an interim outcome. Achieving the interim outcome of inclusive communication requires the effective implementation of the RCSLT's Five Good Communication Standards or the 6 Communication Support Principles (chapter 6), or some amalgam of both. But our overall ultimate outcome is that by achieving these inclusive communication standards or principles we reduce inequalities and risks for individuals with SLCN. More information on the Theory of Change Model can be accessed on the RCSLT webpage.

In order to achieve the interim outcome of inclusive communication, SLTs will deliver the myriad of activities outlined in chapter 7. However, to date there is limited information on the impact of inclusive communication activity in respect of either interim or ultimate outcomes for individuals, services or organisations or communities.

8.1 Examples of impact from the RCSLT member surveys

The RCSLT member survey provided many examples of speech and language therapy activity, working together with other key stakeholders. Examples included activities about developing a range of resources to meet differing needs and this is exemplified by one response:

> "We have been involved in safeguarding projects, including an easy read photo book about getting arrested, easy read safeguarding adult's process including ABE, PIA and special measures, easy read information about deprivation of liberty and different restrictions, eg, continual observation. However we have also developed bespoke resources for individuals such as their risk assessments, protection plans and supervision and treatments orders. Alongside this we provide an accessible training course 'Keeping YOU

Safe' to raise awareness of abuse for services users. We have developed a safeguarding adults Talking Mat resource."

These activities ensure effective use of information. This is key to achieving the ultimate outcome for individuals with inclusive communication needs – the need to access and act on information to make important life decisions. This ultimate outcome can only be achieved together with key stakeholders. The importance of co-production and working with stakeholders was demonstrated by examples of projects provided in response to the RCSLT member survey, with three respondents outlining the following examples:

- A service to tertiary surgical hospital
  The aim was to share information with staff about patients admitted to hospital with known communication needs to ensure staff are aware of their individual skills and difficulties. This was achieved through information gathering with the patient, family and local services and the development of a communication passport or information sheet. If specific materials were also needed (eg, specific symbols, signs, adaptation to a VOCA, visual timetable, etc.), this was also put in place. Staff were trained to be aware of communication difficulties and strategies to support patients. A user audit of the communication passport service was carried out with positive findings.

- Good Information Group (GIG)
  A group meets three times a year and has membership of service users, staff and carers from across all services for adults with learning disabilities. The group has developed inclusive communication standards and audited these standards. They share good practice on how to achieve the standards, hold showcase events and develop inclusive communication projects and resources. Inclusive communication resources developed include easy read photo book 'going to accident and emergency', hospital passport, personal place mat, photographic menu, accessible signage, sensory stories, easy read service leaflets.

- Communication Champions
  SLTs worked together with a local social care provider to increase staff awareness of communication support needs of people with severe and enduring mental health problems, to increase their skills and confidence in using communication support techniques. They used a mixture of training sessions, workplace support and regular forums for sharing learning and problem solving with peers.

8.2 Measuring the impact of inclusive communication

Despite growing inclusive communication practice, the impact of inclusive communication has not been the focus of formal primary research to date. However there is some evidence across the profession of the impact of inclusive communication at different levels. The RCSLT member survey pre-dated the publication of the Five Good Communication Standards; however from the survey we know that 15% of respondents had developed local inclusive communication standards. These had mainly been developed as multiagency standards, co-produced with service users and carers. More than half had audited their standards to measure how successfully standards have been implemented, highlighted areas of good practice and helped share information. One third reported positive findings and one third reported anecdotal/informal positive evidence. The member survey asked for detail about any evaluated inclusive communication projects and the following examples of evaluation of inclusive communication standards were received:

- Using client and volunteer surveys alongside assessment scores of clients, positive outcomes are recorded year on year.

- A number of audits have highlighted positive implementation across homes and day centres. These include auditing coordinator roles and effectiveness, client's views and the views of organisations. All audits have received excellent feedback. All partner agencies have signed up to inclusive communication and it is now systemic and a recognised part of the tendering process. It is mandatory that all staff have foundation level training.

- One audit of communication passports showed that 100% of staff who responded:
    - felt it had helped them to communicate with the child/young person
    - would like to see more passports in the hospital setting
    - that it helped staff to care for the child/young person

  One hundred percent of families who took the passport home with them after the hospital stay also reported they had used the passport since leaving the hospital setting (eg, with carers/respite settings).

- Audits have shown increased awareness of inclusive communication and an increase in the standards being achieved by services.

- Positive outcomes for levels of staff confidence, and quality of life and recovery indicators for people with mental health problems.

- Staff and parents trained: evidence of better understanding and inclusion in church life.

However, stakeholders' report considerable differences and inconsistencies in implementation (Mander, 2015). The publication of the RCSLT Five Good Communication Standards and the Scottish Principles of Communication (chapter 6) should improve consistency and support the development of a greater evidence base. This evidence base will further improve through consistent use and definition of terminology and a clear understanding that inclusive communication is a process and not a resource. This foundation will allow comparative evaluation of different speech and language therapy approaches to implementing inclusive communication practice and help to create an evidence base which distinguishes good practice from 'less good' practice. Using common terminology and standards locally will make it easier to compare service evaluations, audits and research findings. Below is an example of an audit project using the Five Good Communication Standards:

'Using an audit tool based on the Five Good Communication Standards, a service demonstrated good progress towards being a communication friendly and accessible environment for people with intellectual disabilities and SLCN. It demonstrated improved staff awareness of what good communication looks like in practice. Staff developed specialist skills and roles within their team. The audit demonstrated improved team knowledge around two residents and their communication strengths and needs, thus improving the quality of care they receive.

The directors were very positive about the achieved outcomes and a subsequent CQC inspection. The service manager reported "I was able to show them the work and talk about the Five Good Communication Standards and this went down really well"'.

8.3 Methods to measure impact

Future evaluation, audit and research of inclusive communication approaches are paramount. We need to understand what speech and language therapy activities we provide and what the interim outcome is. Long term we need to demonstrate that speech and language therapy activities and achieving inclusive communication impacts on the ultimate outcomes for people with SLCN.

SLTs need to apply one or a number of a variety of methods to measure the impact of inclusive communication practice with individuals, environments,

services, organisations, communities and populations. Methods that could be applied include:

- **Patient Reported Outcome Measures** (PROMs) - aim to assess the quality of care delivered. This method focuses on evaluating the disabling effects of SLCN as reported by the individual. PROMs involve asking individuals about their quality of life before and after inclusive communication interventions.
- **Patient/service user feedback -** this method uses patient feedback to improve services and includes initiatives such as the Friends and Family Test (FFT) and 360° feedback. The FFT evaluates whether individuals would recommend local speech and language therapy services to their friends and family, whereas 360° feedback explores what individuals think about their SLT.
- **Patient-led assessments of the care environment (PLACE)** is a system for assessing the quality of patient environments. Traditional NHS PLACE assessments could be adapted to focus on how communication-friendly health and care environments are to individuals with SLCN.
- **Communication partner confidence questionnaires** can be used to collect quantitative data from communication partners pre and post interventions. This data can be used to evaluate the effectiveness of specific inclusive communication interventions, for example, training, peer support and clinical supervision. Questionnaires should be designed to cover specific topics covered in the inclusive communication interventions, for example, confidence in screening an individual's symbolic development, producing a symbol-based, easy-read resource, using gesture and signing.
- **Training evaluation** - evaluation forms and questionnaires should be used to evaluate the effectiveness of the training to ensure that the training is economically effective and provides the desired outcomes. The evaluation should explore how the trainees reacted to the training, what they learned, how they changed their behaviour and their perceptions of the impact on both their own and user's communication experience.
- **Competency framework -** competencies refer to the knowledge, skills and behaviours that communication partners must have (or acquire) and demonstrate to support inclusive communication effectively. Competency frameworks can be used pre- and post-intervention (such as a rolling training programme) to measure the nature, quality and spread of inclusive communication competences in any given staff team or organisation.
- **Clinical audit** is a way to find out if local services are being provided in line with standards and lets others know where their service is doing well, and where there could be improvements. Services should audit

themselves against national drivers such as the Scottish Government's "Talk for Scotland" Communication Principles and/or Principles of Inclusive Communication or RCSLT Five Good Communication Standards. In England, services will be required to measure performance against NHS England Accessible Information Standards.

- **Observation checklists -** an observation checklist is a list of things that an observer is going to look at when observing an environment. The checklists not only give an observer a framework for an observation but can also serve as a feedback form and contract of understanding with the communication partners. Repeated use of the same checklist pre intervention and at regular intervals post intervention could provide a useful source of data and learning tool for both the SLT and the services they are working for.
- **Patient stories** - allow for a more detailed evaluation of an individual's experience of inclusive communication interventions. Interviews are used to collect descriptive information. There are two main rationales for using patient stories. First, they can be used to celebrate good practice and highlight positive experiences of inclusive communication interventions. Second, they can be used to highlight difficulties or barriers with inclusive communication interventions, so that lessons can be learnt (see Inclusive Communication webpage for case studies).
- **User led "Secret Shopper" evaluations** - an NHS Education Scotland Project, Through a Different Door, supported people with communication support needs (with support from Talking Mats, Ltd.) to rate communication access to various NHS Scotland services. The approach used for this user evaluation of inclusive communication practice is available here.
- **Economic impact assessment** - this method of evaluation considers the efficiency of inclusive communication interventions and whether they represent value for money. Cost-benefit analysis (CBA) is a method for comparing the costs and effects of an intervention in monetary terms. CBA is based on three elements: the effects of the intervention, the costs associated and the benefits of the intervention (ie, health and social care cost savings and quality of life gains). Prevention and local population health needs, as reported in local joint strategic needs assessments, can also be considered with economic evaluations.

9. Future steps

This position paper makes the case for inclusive communication and highlights the risks of communication exclusion. It introduces the umbrella term 'inclusive communication' for consistent understanding by SLTs across the nations and specialisms and contextualises documents such as the RCSLT Five Good Communication Standards and the Scottish Government 6 Communication Support Principles. It identifies the roles that SLTs may play at the different levels for individuals, environments, services and organisations and at a community or population level. It also highlights the gap in primary research but demonstrates the growing body of qualitative evaluation and audit. It identifies the need to evaluate the impact of inclusive communication and the different tools to achieve this.

The future for inclusive communication is exciting and SLTs are well positioned to play a key role. The RCSLT Board of Trustees agree that this is a priority area for action (RCSLT Strategy 2015-18) and RCSLT should be among the leaders in defining inclusive communication and outlining best practice. To achieve this, several areas need to be addressed by members of RCSLT. These include:

- Promoting use of consistent terminology within the profession
- Debating inclusive communication practice and subsequently delivering a consensus on quality standards (plus indicators) of inclusive communication best (known) practice across multiple agencies, sectors and communication needs
- Understanding the role and practice of speech and language therapy in conjunction with all the other stakeholders involved in inclusive communication locally and nationally
- Identifying speech and language therapy leaders and advisers in inclusive communication to use as a source of expertise, providing advice and training (introductory to advanced) for SLTs on good practice
- Ensuring inclusive communication is a live topic in both regional and national hubs and CENs
- Continuing to develop a resource on the RCSLT website linking examples of speech and language therapy and other inclusive communication work at the individual, environmental, organisational, service and population or community levels
- Establishing our speech and language therapy teams as communication inclusive, recognising that all SLTs have a role in implementing inclusive communication approaches
- Developing an evidence base which makes the legal, policy and economic case for investment in speech and language therapy inclusive

communication activity. To achieve this, research, evaluation and audit must be encouraged regarding:
    - What constitutes good inclusive communication practice
    - How SLTs can effectively support others to change their communication, through their speech and language therapy activities, leading to interim and ultimate outcomes for people with inclusive communication needs (see RCSLT Theory of Change Model webpage)
    - What the impact of speech and language therapy inclusive communication practice is - on whom and why
- Sharing inclusive communication evidence through presenting and publishing findings, including small-scale, single case study designs
- Using this evidence base to know what good speech and language therapy inclusive communication practice looks like and promoting consistent implementation of this, by developing guidance for SLTs on establishing good practice across all three levels, and agree evidence-based inclusive communication good practice standards and measurable indicators
- Identifying our local stakeholders and service users as partners to share this position paper, consult on and co-produce locally-relevant inclusive communication models

Addressing the above points will facilitate an evidence-based approach to inclusive communication, and the economic impact of SLTs working with inclusive communication for individuals, environments, services and organisations, and whole communities and populations.

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Belfast Health and Social Care Trust

Standards and Guidelines Committee

Food, fluid and nutrition policy - adult in-patient setting.	
Summary .	This policy outlines best practice guidance for ensuring the establishment and maintenance of adequate food, fluid and nutritional status of our adult in-patients from admission to discharge. It identifies the processes necessary for successful delivery of adequate hydration and good nutrition throughout the organisation and embraces the principle of creating a culture and environment where food, fluid and feeding are recognised by staff, patients and relatives as a fundamental need and mutual responsibility. It provides details of the Malnutrition Universal Screening Tool (MUST) which is designed to help identify adults who are underweight and at risk of malnutrition, as well as those who are obese.
Operational date	June 2011
Review date	June 2013
Version Number	V1
Director Responsible	Brenda Creaney, Director of Nursing and User Experience
Lead Author	Audrey Dowd
Lead Author, Position	Senior Manager Performance Management & Quality Assurance
Department / Service Group	Central Nursing
Contact details	[redacted] Tel No: [redacted]
Additional Author(s)	[redacted] Tel No: [redacted]

Reference No	SG 44/11
Supersedes	All legacy policies

Version Record

Date	Version	Author	Comments
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March 2011	0.2	Audrey Dowd	2nd Draft
April 2011	0.3	Audrey Dowd	Comments from wider circulation
May 2011	0.4	Audrey Dowd	Further Comments
June 2011	0.5	Audrey Dowd	Comments from Dietitics
June 2011	0.6	JR Johnston	Editing
July 2011	0.7	JR Johnston	Final version
30 July 2011	0.8	C Murphy	Add applicability to discharged patients remaining on ward.
July 2011	1.0	Audrey Dowd	Final Policy, fluid

Policy Record

		Date	Version
Author (s)	Approval		
Director Responsible	Approval		

Approval Process – Clinical Standards and Guidelines

Standards and Guidelines Committee	Approval	July 2011	V1.0
Policy Committee	Ratify	July 2011	V1.0
Executive Team	Authorise	July 2011	V1.0
Appropriate Director	Sign Off	July 2011	V1.0

Dissemination

Areas :	

Full Description

1 **Food, fluid and nutrition policy - adult in-patient setting.**

2 Introduction:

It is a basic human right to be free from thirst or hunger although they can occur in hospital as part of a specific therapy plan. There is unequivocal evidence that good food, fluid and nutrition practices are required to support recovery from illness and promote health.

Inadequate hydration can be a common problem in hospitals. Good hydration is important for the safety and wellbeing of hospital patients. Medical evidence shows that it can assist in the management of a number of conditions including diabetes, pressure ulcers, constipation, urinary tract infections and kidney stones. Dehydration has been shown to double the mortality of patients admitted to hospital with a stroke and increase the length of stay for patients with community-acquired pneumonia.

Malnutrition, in particular under-nutrition, is a common problem on admission and can increase during a patient's stay. It can adversely affect clinical outcomes for patients, increases morbidity and mortality, prolongs length of stay in healthcare environments and increases costs of care. In order to treat the condition it needs to be identified. Evidence exists that it is currently under recognised and therefore under treated.

It can also apply to the obese patient whose dietary choices are excessive and imbalanced from an energy perspective and therefore lacking in essential nutrients. Poor nutritional status will compromise recovery in the obese patients as well as those patients who are undernourished."

It is a fundamental requirement of those who deliver healthcare to ensure good hydration and nutritional practices. All clinical staff in the BHSCT play a crucial role in achieving and maintaining excellence in relation to providing adequate food, fluid and nutrition.

This policy embraces the principles in the "Get your 10 a Day, The Nursing Care Standards for Patient Food in Hospital" (appendix 1).

3 Purpose:

The purpose of this policy is to provide staff with guidance to optimise the care of patients' food, fluid and nutrition during their stay in hospital.

4 The Scope:

This policy applies to all Trust employees who are involved in the provision of food, fluid and nutrition in adult in-patient settings

5 Objectives:

The objectives of this policy are to ensure that:

- Patients have their food, fluid and nutrition needs assessed whilst in the care of the Trust.
- Patients experience excellence of care in all aspects of food, fluid and nutrition.
- Patients at risk of malnutrition are identified as soon as possible.
- Patients identified as 'at-risk' receive the most appropriate nutritional therapy.
- A multidisciplinary approach to food, fluid and nutrition is adopted.
- Food, fluid and nutrition standards are regularly monitored and audited.

6 Roles and Responsibilities:

It is the responsibility of all Trust employees who are involved in the provision of food, fluid and nutrition to patients to adhere to this policy.

It is the responsibility of individual staff to identify any knowledge or skills deficits in relation to the policy and take appropriate action.

In a ward setting, the nurse-in-charge has been identified as having the primary role in promoting and ensuring compliance with the practices as set out in this document.

7 The definition and background of the policy:

The prevalence of malnutrition is high with:

- 40% of all patients admitted to hospital are malnourished on admission and this has the potential to increase during their stay (Elia & Stratton). These figures are supported locally by an audit carried out on the Royal site (BHSCT) which showed that more than 35% of patients admitted were malnourished or at risk of developing malnutrition during their stay in hospital.
- Over 10% of all older people being affected by malnutrition (BAPEN 2006).
- 60% of older people admitted to hospital being at risk of becoming malnourished or their situation getting worse whilst in hospital (BAPEN 2006).
- The cost of malnutrition is estimated at over £13 billion per year; over half which is expended on people aged 65 years and over (BAPEN).

Malnutrition is treatable and often preventable. In order to treat the condition it needs to be identified. Evidence exists that it is currently under recognised and therefore under treated.

8 Policy statements:

8.1 All patients will be screened on admission or at an appropriate opportunity, within 24 hours, to assess their nutritional status, using Malnutrition Universal Screening Tool (MUST) - appendix 2.

The following are exempt:

- All dialysis patients admitted to BCH (already under the dietitian care.)
- All patients admitted on enteral feeding (refer to dietitian on admission).
- All patients admitted on parenteral feeding (refer to dietitian on admission).
- All patients in ICU.

8.2 Robust plans of care will be developed for those deemed at nutritional risk. These will include advice and support by appropriate members of MDT.

8.3 All patients remaining in hospital for more than one week will be re-screened as per MUST.

8.4 Where concerns are identified in relation to nutritional intake, patients will have MUST undertaken more frequently.

Within a palliative care context it may not be in the patient's best interest to weigh him/her on a weekly basis as this may only serve to reinforce the unavoidable anorexia and cachexia often experienced with advanced, incurable disease.

When a patient is on a nutritional plan of care, weekly weights may be indicated to

monitor outcomes.

8.5 Patients found to be at low risk of malnutrition will be offered the normal menu including snacks and beverages appropriate to their cultural and religious requirements.

8.6 Patients requiring a special therapeutic diet should be placed on the appropriate menu where available and referred to the dietitian, when indicated.

8.7 Catering department should be notified about the needs of patients who require a special diet based on cultural/religious beliefs.

8.8 Appropriately modified or fortified diet or oral nutritional supplements will be available for patients who require these, following assessment by Speech and Language Therapist and Dietitian.

8.9 The dietitian will liaise with all relevant healthcare professionals ensuring that nursing, medical, catering and pharmaceutical staff are informed of any specific dietary requirements.

8.10 Food will be nutritious and served in appropriate and appetising manner.

8.11 All food preparation will comply with food safety legislation.

8.12 A **protected meal time policy** will be applied across the Trust to allow patients to eat without interruption.

- All staff to be aware of and adhere to the protected mealtime policy.
- Non-urgent activities such as cleaning, non-priority treatments, ward rounds, investigations visiting etc. to be designed to operate around and outside of pre-set meal times.
- Staff and visitors respect the patients' mealtimes as a time focused on the patient.
- Family /carers who **are** offering support and assistance to the patient are encouraged and permitted to be present at mealtimes.

8.13 Where a written sign is used at the bed or on the whiteboard to indicate a special diet, the description must be appropriate and preserve the patient's dignity and privacy at all times.

8.14 The nurse-in charge will be responsible for ensuring patients are offered assistance when needed in choosing from the menu whilst ensuring the preferences of individual patients are respected.

8.15 Where appropriate toileting and/or hand hygiene facilities will be made available before and after meals.

8.16 The nurse-in charge will be responsible for ensuring an environment conducive to eating in a calm and un-hurried manner.

8.17 The nurse-in-charge will ensure that adequate preparation is made before meals; the patient is ready to eat in a safe and comfortable position and food within reach.

8.18 In keeping with the principles in the "Get your 10 a Day, The Nursing Care

Standards for Patient Food in Hospital" (appendix 1) those patients who require support with eating and drinking will be identified using a clear system of identifying such patients e.g. coloured napkin/coloured tray; and they will receive assistance when it is required.

The nurse-in-charge will allocate a member of the team to assist patients who require help with eating and drinking, ensuring the availability of specially adapted equipment and assistance with condiments etc where required. This will be undertaken in a manner commensurate with their needs and dignity.

8.19 The nurse-in-charge will ensure that oral hygiene and denture care needs have been met.

8.20 Where a patient has been identified as at risk of malnutrition, the meal tray is not removed until intake has been observed and documented by a member of staff.

8.21 Standardised food and fluid charts will be utilised to document fluid and nutritional intake in those patients deemed at hydration or nutritional risk.

8.22 Where a patient's meal is missed, the patient will be offered an alternative meal or snack from the snack menu as near to the meal time as possible.

8.23 Where clinically appropriate, the patient will have access to fresh drinking water at the correct temperature at all times.

8.24 Relatives/carers who wish to provide support and assistance at meal times can do so following agreement with the nurse-in-charge.

8.25 The nurse-in-charge must ensure ongoing engagement with patients and carers about the mealtime experience and any nutritional concerns identified.

8.26 Patients in the Emergency Department pending admission will receive the same meal schedule and be offered the same choice of hot meals as the ward in-patient.

8.27 Patients who have been discharged but are remaining on the ward until their transport / carer arrangements are in place will receive the same meal schedule and be offered the same choice of hot meals as the ward in-patient.

8.28 Any special dietary requirements or nutritional risks will be identified and will form an obligatory part of any medical/nursing discharge summary. This information will be reported to any relevant healthcare professional in the community and carers of the patient.

9 Source(s) / Evidence Base:

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NHS Quality Improvement Scotland (2003), 'Clinical Standards: food, fluid and nutritional care in hospitals'.
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DHSSPSNI &~RCN NI (2007), 'Get Your 10 a Day! The nursing care standards for patient food in hospital'.
http://www.bapen.org.uk/must_itself.html

10 References, including relevant external guidelines:

Balvelaar et al. (June 2008), 'Diagnosis and treatment of (disease-related) in-hospital malnutrition: The performance of medical and nursing staff'. Clinical Nutrition Vol. 27, (issue 3), pg 431-438.
BHSCT policy, 'Food Hygiene Standards for Non-Catering Staff.

12 Consultation Process:

Associate Directors of Nursing
Co-Directors of Patient & Client Support Services
Nutrition and Dietetics Department
Patient Client Council
Senior Manager, Public & Patient Involvement.

13 Equality and Human Rights screening carried out:

In line with duties under the equality legislation (Section 75 of the Northern Ireland Act 1998), Targeting Social Need Initiative, Disability discrimination and the Human Rights Act 1998, the Belfast Trust has carried out an initial screening exercise to ascertain if this policy should be subject to a full impact assessment.

☐ Screening completed
No action required.

☐ Full impact assessment to be carried out.

14 Procedures:

Appendix 1 = Get your 10 a Day, The Nursing Care Standards for Patient Food in Hospital
Appendix 2 = Malnutrition Universal Screening Tool (MUST).
Appendix 3 = Step 1: BMI score
Appendix 4 = Step 2: Weight Loss score

Director Brenda Creaney

Date: July 2011

Author Audrey Dowd

Date: May 2011

Appendix 1

The 10 nursing care standards for provision of patient food in hospital



All patients admitted to hospital are screened for risk of malnutrition.



Following screening by nurses, patients who are identified as malnourished or at risk of malnutrition are referred for and receive a nutritional assessment appropriate to their level of need.



Patients who require nutritional intervention will have a nursing care plan devised, implemented, evaluated and renewed to reflect the patient's nutritional and physical care needs and which documents both the dietetic plan and the nursing care assessment.



Patients who require food and/or fluid intake to be monitored will have that activity carried out in a way that is informative, accurate and up-to-date.



Patients who require support with eating and drinking are clearly identified.



Patients who require support with eating and drinking receive assistance when it is required.



Patients will be served their food and allowed to eat their meals without disruption.



Patients receive their meals in a physical environment that is conducive to enjoying their food.



Patients are offered a replacement meal if they miss their meal for whatever reason and can access snacks at ward level.



The patient receives food presented in a way that is appealing and appetising.

PAGE 7

From: Get your 10 a day! The Nursing Care Standards for Patient Food in Hospital – DHSSPSNI – November 2007

Appendix 2

Malnutrition Universal Screening Tool (MUST)

Height ……m **Actual** ☐ **or** **Recalled** ☐
Weight ……kg **Actual** ☐ **or** **Recalled** ☐

Pre-MUST Questions:

Does the patient have:-	**Date:**	**Date:**	**Date:**
1. A history of recent weight loss?	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
2. Altered/decreased appetite for 7 days or more?	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
3. A risk of under nutrition due to current illness? e.g. difficulty eating/drinking	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
4. A need for assistance with feeding?	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Signature:			

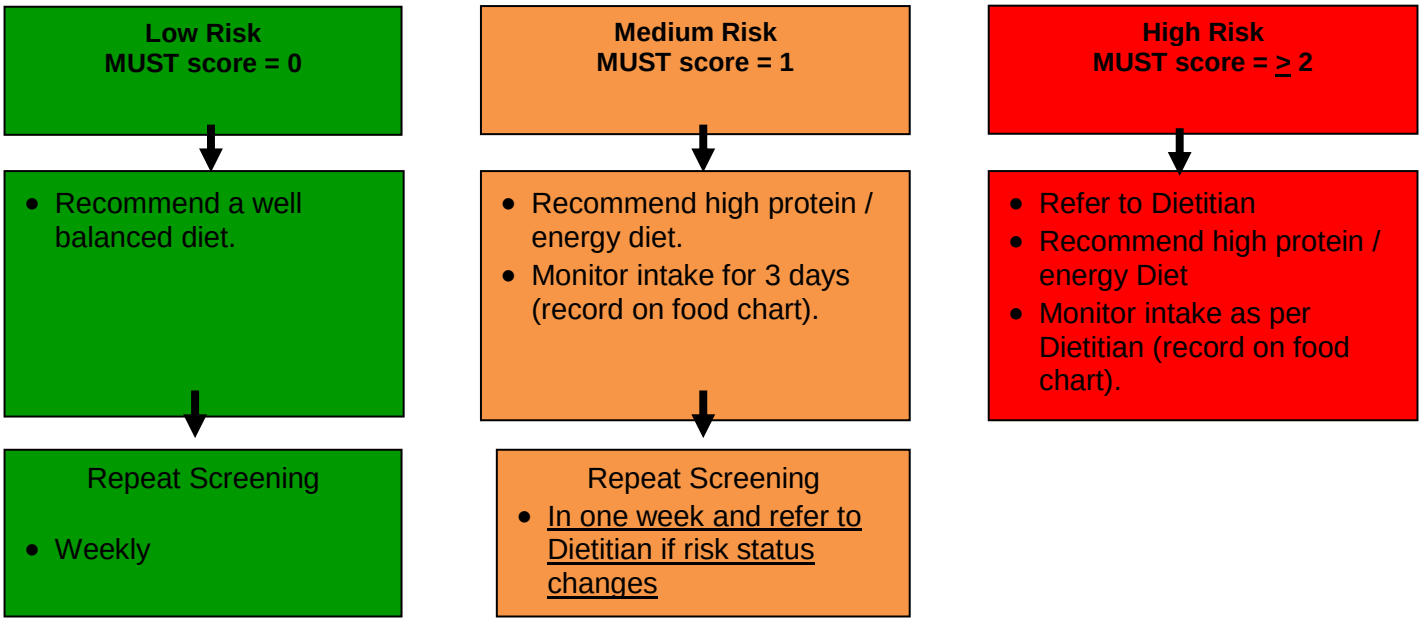
If answer is **No** to any of the above questions repeat screening weekly.

If answer is **Yes** to any of the above questions then complete 'MUST' below. Repeat weekly.

	Date:	**Date:**	**Date:**
Weight (Kg) / MUAC (cm) (Mid Upper Arm Circumference)			
Height (m) / Ulna length (cm)			
BMI			
	Score	**Score**	**Score**
Step 1 - Body Mass Index-BMI			
• Over 20	0	0	0
• 18.5 to 20	1	1	1
• Less than 18.5	2	2	2
Step 2 - Unplanned Weight Loss In Last 3-6 Months			
• Less than 5%	0	0	0
• Between 5-10%	1	1	1
• More than 10%	2	2	2
Step 3 - Acute Disease			
• If patient is acutely ill **and** there has been **or** is likely to be, no nutritional intake for more than 5 days.	2	2	2
Total Must Score:			
Low Risk = 0 **Medium Risk = 1** **High Risk ≥ 2**			
Signature:			

Does the patient require assistance to maintain nutrition and hydration? **Yes** ☐ **No** ☐

Malnutrition Universal Screening Tool (MUST) Flowchart
Management Guidelines



Nursing nutritional plan of care for medium risk patients:

(only applies when patient not already on a therapeutic diet as this can be contradictory to their dietary needs)

- Encourage patient to drink full cream milk.
- Encourage patient to order yoghurt at breakfast.
- Encourage patient to have a dessert/pudding with each meal.Encourage patient to choose a snack if available on the menu.
- Add butter to mashed potato, vegetables etc.
- Avoid low-fat products.
- Aim for three small meals plus 2-3 snacks daily.
- Record food intake on food record chart.

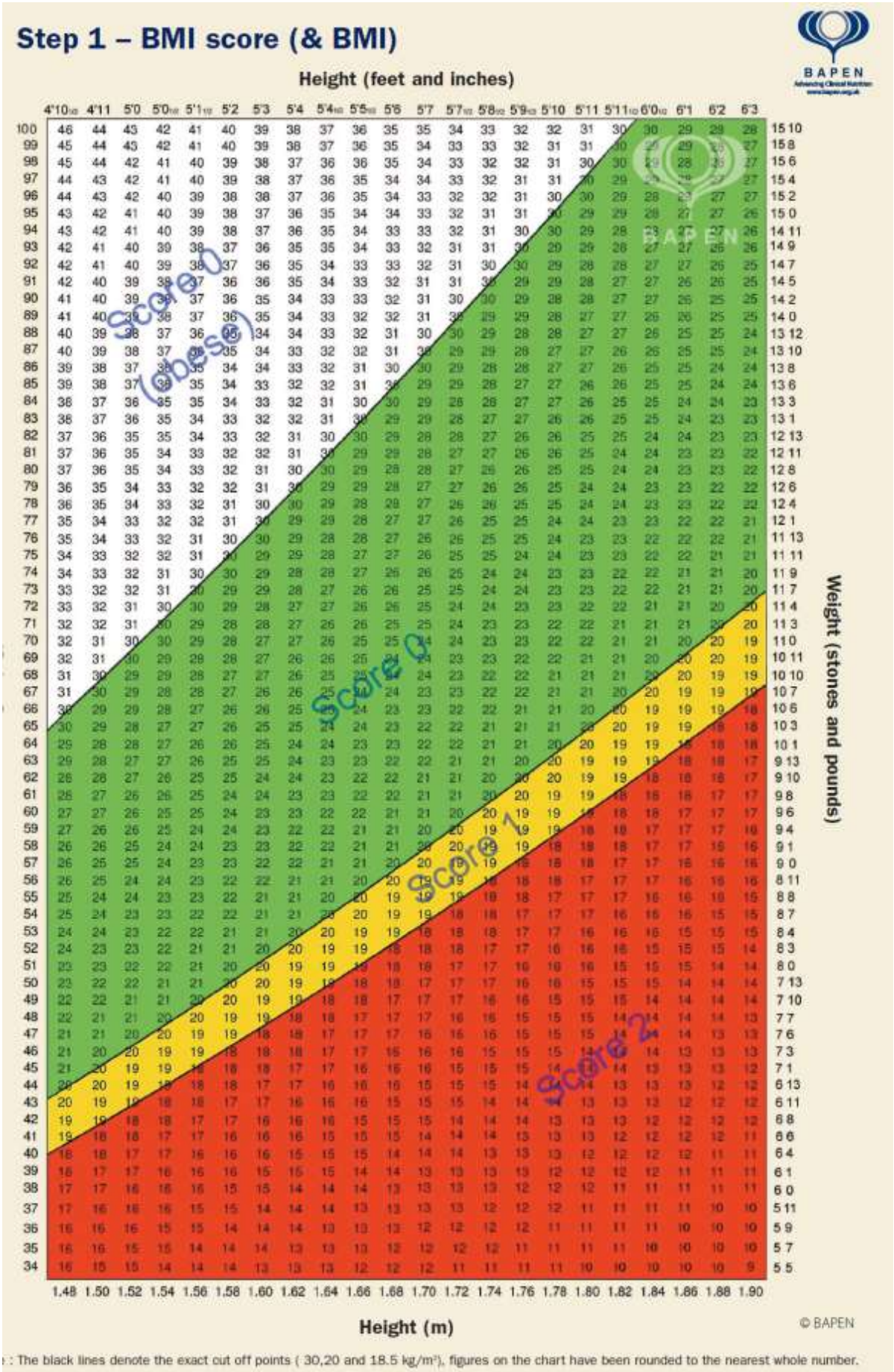
NB: all of these options may not be available in each hospital site.

Exemption from MUST screening on admission to hospital:

- All dialysis patients admitted to BCH (already under the care of the Dietitian).
- All patients admitted on enteral feeding (refer to Dietitian on admission).
- All patients admitted on parenteral feeding (refer to Dietitian on admission).
- All patients in ICU.

NB: some patients with e.g. heart failure, liver disease or who have fluid overload can appear to have a low MUST score and this should be taken into account when making the assessment.

Appendix 3



: The black lines denote the exact cut off points (30,20 and 18.5 kg/m²), figures on the chart have been rounded to the nearest whole number.

Appendix 4

Step 2 – Weight loss score

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Weight before weight loss (kg)	SCORE 0 Wt Loss < 5%	SCORE 1 Wt Loss 5-10%	SCORE 2 Wt Loss > 10%
34 kg	<1.70	1.70 – 3.40	>3.40
36 kg	<1.80	1.80 – 3.60	>3.60
38 kg	<1.90	1.90 – 3.80	>3.80
40 kg	<2.00	2.00 – 4.00	>4.00
42 kg	<2.10	2.10 – 4.20	>4.20
44 kg	<2.20	2.20 – 4.40	>4.40
46 kg	<2.30	2.30 – 4.60	>4.60
48 kg	<2.40	2.40 – 4.80	>4.80
50 kg	<2.50	2.50 – 5.00	>5.00
52 kg	<2.60	2.60 – 5.20	>5.20
54 kg	<2.70	2.70 – 5.40	>5.40
56 kg	<2.80	2.80 – 5.60	>5.60
58 kg	<2.90	2.90 – 5.80	>5.80
60 kg	<3.00	3.00 – 6.00	>6.00
62 kg	<3.10	3.10 – 6.20	>6.20
64 kg	<3.20	3.20 – 6.40	>6.40
66 kg	<3.30	3.30 – 6.60	>6.60
68 kg	<3.40	3.40 – 6.80	>6.80
70 kg	<3.50	3.50 – 7.00	>7.00
72 kg	<3.60	3.60 – 7.20	>7.20
74 kg	<3.70	3.70 – 7.40	>7.40
76 kg	<3.80	3.80 – 7.60	>7.60
78 kg	<3.90	3.90 – 7.80	>7.80
80 kg	<4.00	4.00 – 8.00	>8.00
82 kg	<4.10	4.10 – 8.20	>8.20
84 kg	<4.20	4.20 – 8.40	>8.40
86 kg	<4.30	4.30 – 8.60	>8.60
88 kg	<4.40	4.40 – 8.80	>8.80
90 kg	<4.50	4.50 – 9.00	>9.00
92 kg	<4.60	4.60 – 9.20	>9.20
94 kg	<4.70	4.70 – 9.40	>9.40
96 kg	<4.80	4.80 – 9.60	>9.60
98 kg	<4.90	4.90 – 9.80	>9.80
100 kg	<5.00	5.00 – 10.00	>10.00
102 kg	<5.10	5.10 – 10.20	>10.20
104 kg	<5.20	5.20 – 10.40	>10.40
106 kg	<5.30	5.30 – 10.60	>10.60
108 kg	<5.40	5.40 – 10.80	>10.80
110 kg	<5.50	5.50 – 11.00	>11.00
112 kg	<5.60	5.60 – 11.20	>11.20
114 kg	<5.70	5.70 – 11.40	>11.40
116 kg	<5.80	5.80 – 11.60	>11.60
118 kg	<5.90	5.90 – 11.80	>11.80
120 kg	<6.00	6.00 – 12.00	>12.00
122 kg	<6.10	6.10 – 12.20	>12.20
124 kg	<6.20	6.20 – 12.40	>12.40
126 kg	<6.30	6.30 – 12.60	>12.60

Weight before weight loss (st lb)	SCORE 0 Wt Loss <5%	SCORE 1 Wt Loss 5-10%	SCORE 2 Wt Loss >10%
5st 4lb	<4lb	4lb – 7lb	>7lb
5st 7lb	<4lb	4lb – 8lb	>8lb
5st 11lb	<4lb	4lb – 8lb	>8lb
6st	<4lb	4lb – 8lb	>8lb
6st 4lb	<4lb	4lb – 9lb	>9lb
6st 7lb	<5lb	5lb – 9lb	>9lb
6st 11lb	<5lb	5lb – 10lb	>10lb
7st	<5lb	5lb – 10lb	>10lb
7st 4lb	<5lb	5lb – 10lb	>10lb
7st 7lb	<5lb	5lb – 11lb	>11lb
7st 11lb	<5lb	5lb – 11lb	>11lb
8st	<6lb	6lb – 11lb	>11lb
8st 4lb	<6lb	6lb – 12lb	>12lb
8st 7lb	<6lb	6lb – 12lb	>12lb
8st 11lb	<6lb	6lb – 12lb	>12lb
9st	<6lb	6lb – 13lb	>13lb
9st 4lb	<7lb	7lb – 13lb	>13lb
9st 7lb	<7lb	7lb – 13lb	>13lb
9st 11lb	<7lb	7lb – 1st 0lb	>1st 0lb
10st	<7lb	7lb – 1st 0lb	>1st 0lb
10st 4lb	<7lb	7lb – 1st 0lb	>1st 0lb
10st 7lb	<7lb	7lb – 1st 1lb	>1st 1lb
10st 11lb	<8lb	8lb – 1st 1lb	>1st 1lb
11st	<8lb	8lb – 1st 1lb	>1st 1lb
11st 4lb	<8lb	8lb – 1st 2lb	>1st 2lb
11st 7lb	<8lb	8lb – 1st 2lb	>1st 2lb
11st 11lb	<8lb	8lb – 1st 3lb	>1st 3lb
12st	<8lb	8lb – 1st 3lb	>1st 3lb
12st 4lb	<9lb	9lb – 1st 3lb	>1st 3lb
12st 7lb	<9lb	9lb – 1st 4lb	>1st 4lb
12st 11lb	<9lb	9lb – 1st 4lb	>1st 4lb
13st	<9lb	9lb – 1st 4lb	>1st 4lb
13st 4lb	<9lb	9lb – 1st 5lb	>1st 5lb
13st 7lb	<9lb	9lb – 1st 5lb	>1st 5lb
13st 11lb	<10lb	10lb – 1st 5lb	>1st 5lb
14st	<10lb	10lb – 1st 6lb	>1st 6lb
14st 4lb	<10lb	10lb – 1st 6lb	>1st 6lb
14st 7lb	<10lb	10lb – 1st 6lb	>1st 6lb
14st 11lb	<10lb	10lb – 1st 7lb	>1st 7lb
15st	<11lb	11lb – 1st 7lb	>1st 7lb
15st 4lb	<11lb	11lb – 1st 7lb	>1st 7lb
15st 7lb	<11lb	11lb – 1st 8lb	>1st 8lb
15st 11lb	<11lb	11lb – 1st 8lb	>1st 8lb
16st	<11lb	11lb – 1st 8lb	>1st 8lb
16st 4lb	<11lb	11lb – 1st 9lb	>1st 9lb
16st 7lb	<12lb	12lb – 1st 9lb	>1st 9lb

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Reference No: SG 27/17

Title:	The Prevention & Management of Patient, Client and Service Users with Identified Choking Risks		
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Ownership:	Brenda Creaney, Executive Director of Nursing & User Experience		
Approval by:	Standards and Guidelines Policy Committee Executive team Meeting	**Approval date:**	16/08/2017 04/10/2017 11/10/2017
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Key words:	Choking, Asphyxiation, Aspiration, Dysphagia or Eating, drinking or swallowing difficulties (EDS)		
Links to other policies	• First Aid at Work. • Medicines Code. • Royal Marsden Manual of Clinical Procedures and Policies (access available from the HUB). • Food, Fluid and Nutrition Policy. • Food Hygiene for Non-Catering Staff Policy. • Prioritising the Mealtime Experience Policy. • Adverse Incident Reporting and Management Policy • The Reporting of Injuries, Diseases and Dangerous Occurrences Regulations (NI) 1997 (RIDDOR) Procedural Arrangements. • Use of Restrictive Interventions for Adult & Children's Services		

Date	Version	Author	Comments
19/03/2015	0.1	Karen Cunningham, Karen Devenney, Angela Crocker	
20/11/2015	0.3	K Cunningham, K Devenney, C Donnelly, A Crocker	Amendments following Sub Group Meeting
15/01/16	0.4	Karen Cunningham	Amendments following Group Meeting

16/03/16	0.5	Karen Cunningham / Angela Crocker	Further Group amendments
06/04/16	0.6	Karen Cunningham / Angela Crocker / Catherine Donnelly	Further Group Amendments
21/04/16	0.7	Patient Choking Group	Final Amendments prior to Trust wide consultation
28/07/16	0.8	Karen Cunningham / Angela Crocker / Catherine Donnelly	Sub Group Final amendments
24/11/16	0.9	Karen Cunningham / Angela Crocker / Catherine Donnelly	Amendments before presentation to Standards & Guidelines Committee
10/02/17	0.10	Karen Cunningham / Angela Crocker / Catherine Donnelly / Ana Marie Magorrian	Amendments following discussion with Catering, Community and Acute Ward representatives following action points arising out of Standards and Guidelines Committee 14/12/16
27/4/17 & 24/5/17	0.11	As above	Amendments following feedback of the draft Thematic Review on Patient Choking.
30/06/17	0.12	As above	Amendments following advice from the PHA
02/08/17	0.13	As above	Amendments following advice from SLT
16/08/17	0.14	Karen Cunningham / Angela Crocker / Ana Marie Magorrian	Final amendments following approval at Standards & Guidelines Committee
21/09/17	0.15	Karen Cunningham / Angela Crocker / Ana Marie Magorrian	Amendment from LD operations manager
26/09/17	0.16	Karen Cunningham / Angela Crocker / Ana Marie Magorrian	Easy read guide updated.
05/10/17	0.17	Karen Cunningham / Angela Crocker / Ana Marie Magorrian / Catherine Donnelly	Amendment to Section 6 suggested by Policy Committee.

Policy on the Prevention and Management of Patient, Client, Service Users with Identified Choking Risks

Guide to Key Points in the Policy

"An acute episode in which the patient coughed incessantly or experienced a colour change (with inability to speak or cough effectively) while ingesting food or drink. The solid or liquid usually has to be expelled to terminate the event."

Do your Staff have knowledge of the:

- Available training programmes on the prevention and management of choking and consistency of foods and fluids (Appendix 8)
- Signs and symptoms that may indicate a risk of choking (Appendices 5 & 8)
- National Dysphagia Diet Descriptors. (Appendix 3)

What staff should do following a choking incident

- Ensure immediate care and emergency first aid response to choking.
- Arrange a Medical check.
- Follow "Actions to consider following a choking incident (Appendix 1).
- Complete an incident report.
- Inform NoK, GP and other appropriate external organisations (Appendix 16).
- Complete appropriate assessments and follow up actions (Appendix 16).
- Identify any required changes in practice, share learning and obtain support from Occupational Health Clinical Psychology.

On Discharge

- Include risk of choking on Transition of Care documentation, PARIS, NIECR and Discharge letters.
- Provide education and advice to the client and/or carers (Appendix 3 & 15).
- Ensure placement or service meets the assessed needs of the person (Section G, 3).
- To include a prescription for thickener on discharge (Section 3, A, point 10; Section 4.2 B
- The relevant discharge care pathway should clearly identify the key worker through which all care needs are disseminated.

What staff should do in relation to caring for patients, clients and service users at risk of choking from Eating, Drinking or Swallowing (EDS)?

- Establish if there is a history of, or high risk of, choking at the time of admission e.g. NAPOC.
- Implement the decision making tree for patients with an identified risk of choking (Appendix 2a).
- Record and highlight current recommendations for reducing the risk to staff involved in their care. Speak to the carers/families regarding current plan (e.g. Appendix 9).
- Promote safe eating and drinking strategies (e.g. Appendix 15).
- Referred patients with new or deteriorating EDS problems to Speech and Language Therapy (Appendix 5).
- Clearly display EDS recommendations for staff, family and visitors (Appendices 5, 11 & 12).
- Manage Oral health issues (in Responsibilities Section I).
- Ensure recommended diet and fluids are available and given at all times (Appendix 1 point 15).
- Provide appropriate support and supervision level at mealtimes (Appendix 4).
- Support clients to make risk based decision regarding their choice of food (Appendix 10 & 15).
- Provide medications in a suitable format following discussion with Pharmacy. (Policy page 7, Section 3E and Appendix 7).
- Store food and fluids safely (page 3, point 5).
- Report any variance from EDS care plan using the Datix Incident Reporting System (page 5 point B2.)

1.0 INTRODUCTION / PURPOSE OF POLICY

1.1 Background

Keeping our patients safe in our organisation is a key priority in the Trust's Quality Improvement Plan 2016 – 2020. In May 2014 the Health & Safety Executive (HSENI) advised that if a death or major injury arises due to service user choking (see definition 4.1), in connection with the Trust's work activities, and it could have been prevented by the Trust through risk assessment, identifying and implementing control measures or failure to do any of these, this should be reported under RIDDOR (Reporting of Injuries, diseases and Dangerous Occurrences Regulations (NI) 1997).

Evidence shows that specific groups of individuals who have **eating, drinking and swallowing (EDS)** difficulties, known as dysphagia, have a higher risk of choking. This includes those with a mental health diagnosis, dementia, a learning disability, those with a chronic respiratory conditions, frail elderly with multiple complex health conditions, acquired or progressive neurological conditions and physical conditions. In addition those with behavioural issues are also at risk such as eating quickly, eating other patients' food, a tendency to gulp food and liquids or eating non foods items. Patients are more vulnerable during transition from one service to another.

The Trust is committed to the prevention and management of choking with the full knowledge that choking is complicated, and while some risks can be identified and managed, other risks are complex to manage, and will require collaborative working from specialist areas. Anyone could choke at any time. There will be choking events that cannot be predicted. These low probability high impact choking events have no identifiable risks. Whilst it is not possible to prevent all episodes of choking, working together to reduce the risk of choking and improve the safety of individuals who have EDS is essential.

1.2 Purpose

The purpose of this policy is to develop a resilient system that supports early identification of children and adults who may have an increased risk of choking due to EDS, and develop supports to help manage and reduce that risk.

1.3 Objectives

1. To ensure that staff ask patients, clients or service users if they have any swallowing or choking needs, and find out how to meet their needs. Recognise when a person is at risk and take steps to assess and reduce the risk, this may include appropriate onward referral.

2 To ensure that the needs of patients, clients and service users with any swallowing or choking difficulties are appropriately assessed, steps are taken to reduce risks and relevant onward referral is completed.

3 To share information about people's swallowing and choking needs with other healthcare providers, when they have consent or permission to do so.

4 To ensure that patients, clients and service users receive food and drink which they can safely manage, and to provide the appropriate support they need to eat and drink.

5 To ensure that adequate documentation, using the examples provided in this Policy, are retained for patients, clients and service users with swallowing or choking difficulties.

6 Ensure all staff supporting people with swallowing or choking needs has access to appropriate training this may include eating, drinking and swallowing awareness training, choking awareness and first aid response.

2.0 SCOPE OF THE POLICY

This is a Trust-wide policy applicable to all staff who care for adults and children with eating, drinking and swallowing difficulties and or identified choking risks. It relates to all patients, clients and service users in all Trust Services including Day Care, Residential, Acute in-patient, client/service users and Domiciliary Care, nurseries, schools and home.
An easy read guide to this policy has been developed **(Appendix 17).**

3.0 ROLES/RESPONSIBILITIES

A. Ward, Department & Facility Managers should:

1. Ensure that food provided to patients, clients and service users on a modified dysphagia diet is of the correct consistency, is prepared as recommended and has not altered following preparation.
2. Ensure patients, clients and service users with a choking risk are clearly identified. (See Appendix 1 which can be used as a risk screening tool).
3. Consider referral to SLT for a swallowing assessment using indicators **(Appendix 5)** for all patients, clients and service users who show the symptoms of eating, drinking and swallowing difficulties (EDS) (dysphagia) or choking risk.
4. Ensure that staff have the necessary knowledge to assess the choking risk, make recommendations and take appropriate action to manage and reduce this risk wherever possible. Available Training Programmes (**Appendix 8**).
5. Ensure adequate storage arrangements to prevent accidental ingestion of prohibited food items including thickening agents. (Refer to Section 7 References).
6. Ensure that the general advice to help someone take medications when they have a choking risk is communicated to and implemented by all staff **(Appendices 7 & 15).**
7. Refer patients, clients and service users to the appropriate member of the multidisciplinary team for assessment and recommendations when any of the following impact on their risk of choking:
   a) difficulty taking medication or suspected side effects from medication
   b) breathing difficulties or recurrent chest infections
   c) difficulty maintaining a stable upright position while eating and drinking
   d) difficulty independently feeding
   e) oesophageal symptoms for example increased reflux
   f) dental pain, dental related oral swelling, loss of or ill- fitting dentures, damage to the dentition (teeth).
8. Implement the 'Prioritising of Mealtime Experience Policy'.

9. Ensure that a Malnutrition Universal Screen Tool (MUST) has been completed accurately. MUST will identify patients at risk of malnutrition. Malnutrition may have a negative impact on an individual's ability to swallow. Patients with a deteriorating swallow which is likely to significantly impact on nutritional intake should be referred to dietetics **following** assessment by SLT. Advice should be sought from a Dietitian, through local referral arrangements, where there are nutritional or hydration concerns following commencement on a texture modified dysphagia diet. (**Appendix 3).**

   Patients should be referred to the Dietetic Service in the following circumstances:

   - with an accurate MUST score of 2 or above, this score identifies patients at risk of malnutrition. Malnutrition may have a negative impact on an individual's ability to swallow or a deteriorating swallow may cause a patient to develop malnutrition.
   - when commenced on a texture B or C diet following assessment by a SLT
   - with a MUST score of 2 and above and commenced on a texture D or E diet following assessment by a SLT.
   - who are consuming teaspoons amounts of food or nothing orally for a period of 5 consecutive days following SLT assessment.

10. Ensure that discharge planning were required includes a prescription request for thickener forwarded to the GP and to provide an interim supply as per local arrangements.
11. Ensure SLT recommendations/care plan are shared with relevant parties on patient/client/service user discharge or transfer.
12. Educate and support patients, clients and service users on how to avoid and/or modify high risk choking foods, adopt safe eating behaviours and foster safe eating environments to help reduce their risk of choking **(Appendix 15).**
13. Ensure staff have considered and recorded actions following choking events to help prevent further choking. **(Appendix 1).**
14. Ensure the correct reporting of all choking episodes where the patients, clients and service users suffers harm in accordance with the Adverse Incident Policy. Any incidence of sudden death, including death by choking must be reported to the PSNI and to the Safeguarding Unit and RQIA.
15. Ensure that all alerts, newsletters and safety briefs are brought to the attention of all staff.
16. Ensure choking risks are reflected on Service Area/Directorate Risk Registers.
17. Ensure staffing levels and skill mix are adequate to support patients, clients and service users eating and drinking **(Appendix 4 & 8)**.
18. Complete a Choking / Dysphagia risk assessment for patients, clients and service users with identified choking risks. (Sample risk assessment **Appendix 2 a, b & c)**.
19. Ensure that staff working with high risk patients, clients or service users are aware of their roles and responsibilities in managing the associated risks and have access to adequate training.
20. Send representatives to the relevant Catering User Groups organised by the Catering Managers and held on various Trust Sites; to highlight and address any issues.
21. Advise the relevant Catering Manager of any incidents of concern associated with meals received.
22. Ensure robust systems are in place for timely sharing of information with other services, e.g. food providers. Systems in place to ensure information is highlighted or flagged up for any individual with a known choking risk or EDS

difficulty, that is transferred or discharged from a service e.g. an alert is available on Paris to highlight swallowing difficulties.

23. Ensure that staff are aware of specific diet textures and feeding protocols for individual patients, clients and service users.
24. The discharge care pathway should clearly identify the key worker through which all care needs are disseminated.
25. Ensure that required changes in practice are identified as a result of incident investigations and that learning is shared with other relevant services.
26. Ensure adequate emotional and professional support is available from colleagues, line managers and the Occupational Health Psychology Services for frontline staff involved or exposed to a patient choking event.
27. Provide support or alternative formats in terms of communication support or linguistic needs, if required, to communicate the policy.

B. Staff involved in patients, clients and service users care should:

1. Be involved in the care planning process for people at risk of choking.
2. Be aware of the consequences of not following an agreed eating, drinking and swallowing care plan. Staff should report, in discussion with their managers, all incidents where eating, drinking and swallowing care plans were not followed placing the person at risk, e.g. person given wrong food/drink, this would include near misses. Staff should follow incident reporting policy.
3. Consider referral to SLT for a swallowing assessment using indicators **(Appendix 5)** any time eating, drinking and swallowing (EDS) concerns are raised or a new risk of choking is suspected on oral intake.
4. Support the patients, clients and service users to make a risk based decision regarding their choice of food where possible. **Refer to section 4 for further information on Risk Feeding.**
5. Have adequate training to be able to recognise and know how to prepare/present food and fluids to the patients, clients and service users according to their eating and drinking recommendations. **(Appendix 8).**
6. To have adequate training to be able to recognise inappropriate food for the patient/service users; particularly when assisting with feeding.
7. Show awareness of the risk of choking and the steps that can be taken to reduce risk.
8. Ensure knowledge and competence in the first aid response for choking including those patients, clients and service users who are wheelchair users. **(Appendix 15).**
9. Be aware of when and how to report choking. Report all choking events that require intervention that could have resulted in harm. An example of a record of all actions to consider following a choking incident can be found in **Appendix 1.** This form can be used to evidence what actions have been considered to help reduce the risk of further choking and to support risk management plans. A copy should be retained in the patients, clients and service users notes.
10. Be aware of how to access resources and specialist healthcare professionals that can help reduce risk of choking in relation to dysphagia, unsafe eating behaviours, positioning, respiratory or chest care, medication prescribers, advocacy. GI/reflux management and oral health. This may include SLT, OT, Physiotherapy, Pharmacy, Medical and Dental staff.

11. Be aware of the national dysphagia diet texture descriptors and have access to NIHSC Swallowing advice dysphagia diet advice leaflets based on this guidance **(Appendix 3).**
12. Ensure capacity and consent has been considered, https://www.health-ni.gov.uk/articles/consent-examination-treatment-or-care If a person with identified choking risk is assessed as not having capacity and is restricted from accessing food/areas, e.g. locked kitchens or kitchen cupboards ensure consideration has been given to the Mental Health (Northern Ireland) Order 1986.
    Guidance on the principles to be applied by those involved in taking decisions about an individual's care and treatment that might result in the deprivation of that individual's liberty can be accessed from the Restrictive Interventions for Adult and Children's Services Policy on the HUB.
13. Ensure all decision making is guided by and takes account of individual rights as enshrined in the Human Rights Act 1998 in particular Article 5 (1), 5 (4), Article 8and Article 14.
14. If patients, clients or service users, as a result of their behaviours and the consequent risk of choking, are prevented from accessing high risk foods, consideration should be given to the Mental Capacity Act Deprivation of Liberty Safeguards.
15. To participate in Choking / Dysphagia risk assessment for patients, clients and service users with identified choking risks when indicated. (Sample risk assessment Appendix **2** a, b & c).
16. Key workers in Community Teams should ensure that statutory services that an individual is involved with, are aware of specific swallowing assessments e.g. Day Services, Respite / Short breaks etc.

C. The Speech & Language Therapy Department should:

1. Consider referrals, undertake assessments and produce care plans for people at risk of choking due to oral-pharyngeal dysphagia.
2. To communicate the risks of choking to patients, clients and service users with identified eating, drinking and swallowing (EDS) difficulties (dysphagia) and their staff and carers.
3. Work with the multidisciplinary team to optimise safety, nutrition and hydration. Make onward referrals to MDT as necessary e.g. Dietetics.
4. Provide Eating, Drinking and Swallowing awareness training to staff and patients, clients and service users.
5. Contribute to capacity assessments in relation to the risk of choking **(**Example **- Appendix 10).**
6. Should report if they observe incidents where eating, drinking and swallowing care plans were not followed placing the person at risk, e.g. person given wrong food/drink, this would include near misses. Staff should follow incident reporting policy.
7. To contribute to identifying when a Choking / Dysphagia risk assessment is required and participate when appropriate. (Sample risk assessment Appendix **2** a, b & c).
8. Ensure robust systems are in place for timely sharing of information with other services, e.g. nursing homes. Systems in place to ensure information is highlighted or flagged up for any individual with a known choking risk or EDS

difficulty, that is transferred or discharged from a service e.g. an alert is available on Paris to highlight swallowing difficulties.

D. The Catering Department should:

1. Provide food for people on dysphagia modified diets in line with national descriptors.
2. Ensure that as far as possible a choice of modified meal and snacks of the appropriate texture are available. Where modifications cannot be achieved by Catering, further modification may be required prior to serving at Ward level. Food should be checked by staff before serving including the possible presence of small bones.
3. To communicate regularly with services in relation to specific requirements.
4. To work in conjunction with SLT and Dietetics, using national descriptors to ensure foods of the correct consistency which meet the needs of patients with eating, drinking or swallowing (EDS) difficulties (dysphagia) are provided.
5. To access training for staff to ensure the risks of providing inappropriate consistencies are clear.

E. The Pharmacy Service should:

1. Provide advice and individual medication review support when requested.

2. Refer to and discuss with Speech and Language Therapists where patients present with swallowing difficulties and require pharmaceutical advice on suitable alternatives to solid oral medicines. SLTs however do not assess patients who have difficulty swallowing medication only. Be aware that that people can have difficulty swallowing liquids safely and therefore liquid medications may not always be a suitable for patients with swallowing difficulty. (Refer to Appendix 8).
   Note: General pharmaceutical advice for primary and secondary care is available via the Health and Social Care website : Choosing Medicines for Patients unable to take solid oral dose forms

F. The Dietetics Department should:

1. To provide advice to patient, client or service users referred to the service who have been placed on modified diets.
2. Assess the adequacy of texture modified diets in relation to patient's nutritional requirements.
3. Provide advice with regard to manipulating food and fluids to optimise nutritional value and meet nutritional requirements. This will include the provision of supporting literature.
4. Select the correct texture of oral nutritional supplements (ONS) if required following advice provided by SLT.
5. Discuss the need for enteral or parenteral nutrition with the medical team where the patient is unable to meet their nutritional requirements orally.
6. Ensure the patient receives a prescription from their GP when pre-thickened ONS are required for home use.
7. Ensure follow up is arranged as required.

8. Work with catering colleagues to code menus accurately thus ensuring safe choices can be made.
9. Assist staff tasked with helping patients make appropriate food choices by providing a manual which will be available at ward level and electronically.

G. Social Workers and Care Managers should:
Point 6 is also relevant to Key Workers in ALD Community Teams

1. Ensure capacity and consent has been considered.
   If a person with identified choking risk is assessed as not having capacity and is restricted from accessing food/areas, e.g. locked kitchens or kitchen cupboards ensure consideration has been given to the Mental Health (Northern Ireland) Order 1986.
   Guidance on the principles to be applied by those involved in taking decisions about an individual's care and treatment that might result in the deprivation of that individual's liberty can be accessed and http://www.belfasttrust.hscni.net/pdf/Use_of_restrictive_interventions_adults_and_childrens_services.pdf
2. Ensure all decision making is guided by and takes account of individual rights as enshrined in the Human Rights Act 1998 in particular Article 5 (1), 5 (4), Article 8and Article 14.
3. Ensure that the placement or service meets the assessed needs of the person with a choking risk. e.g. staff have adequate training, see matrix **(Appendix 8**). As part of their annual review of placements, must check that individuals are receiving annual dental and health checks.
4. Quality assure that private services have reported all choking incidents and provided copies of incident forms to the trust quality support team.
5. To check if eating, drinking and swallowing care plans are being followed and all non-compliance issues reported during review meetings. Social Work should seek out the Care Plans relating to eating and drinking from SLT and Dietetics as part of the Care Management process. Communication should be timely to ensure that care plans are shared with relevant parties e.g. Care Providers, Nursing Homes and Day Centres.
6. Ensure robust systems are in place for timely sharing of information with other services, e.g. food providers. The systems in place should ensure information is highlighted or flagged up for any individual with a known choking risk or EDS difficulty (including any reassessments) using other services including Day Care, Short Breaks/Respite Care Packages. An alert is available on Paris to highlight swallowing difficulties.
7. To ensure that staff are aware of specific diet textures and feeding protocols for individual patients, clients and service users.
8. To ensure that required changes in practice are identified as a result of incident investigations and that learning is shared with other relevant services.
9. To ensure adequate emotional and professional support is available from colleagues, line managers and the Occupational Health Psychology Services for frontline staff involved or exposed to a patient choking event.

H. The Health & Safety Department should:

1. The Health & Safety Managers will use the following criteria to assist in judging if an incident is reportable or not under RIDDOR, upon receipt of a Trust incident report form and through Datixweb:
2. To organise an external provider for the provision of first aid training for staff throughout the Trust in accordance with the First Aid at Work Regulations (NI) 1981 and associated Approved Code of Practice (refer to the Trust's First Aid at Work Policy for further information).
3. To provide support or alternative formats in terms of disability or language needs, if required, to communicate the policy.

Examples of RIDDOR reportable service user choking events include:

A Service User chokes and dies. This service user has choked previously and is felt to be at risk of choking, but there is no evidence of any assessment or action to reduce the risk.

A Service User chokes on a high risk choking food. They have *been assessed as being at risk of choking and have a care plan stating that they require* supervision when eating *and should be protected from and not have access to certain high risk choking foods.*

An incident may not be reportable if:

a) The service user, whilst vulnerable, was not specifically at risk of choking and was able to make risk-based decisions in relation to what they ate; or
b) The service user choked on something that they were allowed to access to (according to the risk assessment) or
c) The supervision and storage of restricted items was adequate.

I. The Health Improvement Department should:

Raise awareness of choking risk and importance of health promotion in related areas including good oral care, respiratory care, posture and seating.

J. The Dental Department should:

Dental Services provide assessment or treatment for inpatients only, as per their protocol. All other persons with an identified choking risk should be referred to their usual dental service provider e.g. General Dental Practitioner or Community Dental Services.

K. The Occupational Therapy Department should:

Provide a seating assessment, independent feeding assessment and other specialised assessments, such as sensory assessment, where available.

L. The Physiotherapy Department should:

Provide chest assessment and chest physio for people with breathing difficulties and regular chest infections that are contributing to their choking risk.
To undertake physio assessment, post choking incident, if there are concerns regarding aspiration.

M. BHSCT Staff working in non-Trust settings, e.g. schools, private nursing homes, voluntary services etc.

1. All trust staff should be aware of the choking policy and will take appropriate actions when they become aware of a client at risk or who has had a choking incident within a non-trust service.
2. All SLTs working in non-trust settings are aware of and have access to the relevant trust SLT EDS Care pathways and all management of EDS difficulties should follow the relevant pathway.
3. The SLT department offer staff who are responsible for working with clients with EDS difficulties an awareness training session and individual sessions if indicated. This content of this training is now standardised across settings and includes reference to the trust choking policy.
4. Private care providers should be advised of the need to report all choking incidents and provide copies of incident forms to the trust quality support team.
5. Staff should report, in discussion with their managers, all incidents where eating, drinking and swallowing care plans were not followed placing the person at risk, e.g. person given wrong food/drink, this would include near misses. Staff should follow local incident reporting policy for the non-trust setting, record who had been informed and ensure the incident has been reported to relevant parties e.g. care manager.
6. SLT should keep a record of any incident report and agreed actions for the patient file.
7. If appropriate e.g schools settings, SLT will inform manager of non-Trust service that the incident will be reported on Trust systems.

4.0 KEY POLICY PRINCIPLES

4.1 Definitions

Asphyxiation. Choking can lead to asphyxiation when the airway is blocked or closed and air cannot enter the lungs cutting off oxygen to the brain. This can result in a loss of consciousness and can, at times, be fatal.

Aspiration
Where food or drink enters the airway and can result in a choke, asphyxiation and chest infections or pneumonia. Aspiration may be *oropharyngeal* with food or drink entering airway direct from the mouth or *gastroesophageal* as a result of material overspilling or refluxing back from the oesophagus or stomach. Aspiration often results in coughing, spluttering and distress but it can also be silent with no outward signs.

Choking is "an acute episode in which the patient coughed incessantly or experienced a colour change (with inability to speak or cough effectively) while ingesting food or drink. The solid or liquid usually has to be expelled to terminate the event" Fioritti et al 1997.

Dysphagia or Eating, drinking or swallowing difficulties (EDS) is defined as "*difficulty in oral preparation for the swallow or in moving a bolus from the mouth to the stomach*" (RCSLT 1998). Dysphagia is a difficulty swallowing. It is caused by a breakdown in the pharyngeal and/or oesophageal swallowing process due to structural or neuromuscular impairments. Dysphagia can be exacerbated by developmental or behavioural issues which can be common among children and adults with a learning disability or older people with dementia. Dysphagia can lead to food or drink entering the lungs instead of the stomach, this is known as aspiration.

It is recognised that whilst anyone can experience a choking episode there are a number of client groups for whom the risks are magnified, in particular people who have **dysphagia**.

Thickener is a powder added to a liquid or food to make the consistency thicker. Thickeners can be prescribed as a treatment for people who can no longer swallow normal liquids safely.

4.2 Policy Principles

a) Awareness

The Trust will raise awareness of choking risks and the steps that can be taken to reduce the risks. Highlight importance of following care plans for children and adults identified as having an eating, drinking or swallowing difficulty (dysphagia) or choking risk.
Raising awareness includes:

- Recognition of signs and symptoms that may indicate a risk of choking
- Emergency aid response to choking
- Referral processes to SLT or multiagency team
- Food preparation
- Skills to support individuals at risk of choking with their eating and drinking
- Care planning and support to meet individual needs.
- Sample risk assessment proformas

b) Identification and Screening

To ensure that patients, clients and service users at potential high risk of choking are risk assessed, risks documented and appropriate risk management implemented including referral where appropriate.

Ensure all initial admission service documentation has clear questions to identify people with Eating, Drinking and Swallowing (EDS) difficulties or a known risk of choking, e.g. NISAT, NAPOC, About You. These questions should be asked when a person is new to a relevant Service Facility, when there is a change to health which may impact on EDS and also on all reviews.

Services make sure that if someone has a known choking risk or EDS difficulties, this is clear on their notes or records. A clear system to highlight or flag up someone with a choking risk or EDS difficulty, so that all staff are aware and can access a care plan at mealtimes.

Ensure early detection of people who have no known EDS difficulties or choking risk, but are presenting with new difficulties. **(Appendix 9).**

Ensure that all staff can recognise people who may have EDS difficulties or be at risk or choking and know how to escalate concern.

Ensure monitoring of people where choking risks may change due to deteriorating health indicators (**Appendix 5**).

Ensure robust systems are in place for timely sharing of information with other services, e.g. food providers. Systems in place to ensure information is highlighted or flagged up for any individual with a known choking risk or EDS difficulty, that is transferred or discharged from a service e.g. an alert is available on Paris to highlight swallowing difficulties.

c) Risk Assessment

The consent of the person must be obtained wherever possible, before any medical investigation or assessment is undertaken. It is essential that all decisions are clearly documented. When the person is unable to give informed consent follow best interest decision guidelines. The Trust will provide guidance to Ward, Department and Facility Managers, Ward Sisters / Charge Nurses, on risk assessment processes to assess a person's risk of choking and strategies to minimise these risks within their areas of responsibility. Staff should use the Trust standard risk form, a locally agreed risk form or the adapted NPSA risk form in **Appendix 2 b**. SLT assessment and care plan may be also be part of the risk assessment action plan. A risk assessment should be completed for all patients who have a risk of a choking episode. The NPSA is a more comprehensive assessment for use in complex management.

Appendix 9 highlights an example of good practice when someone is highlighted as having a choking risk. (An example of a completed Choking Risk Assessment form adapted from the NPSA is available at **Appendix 2 c**).

d) Reporting and Learning

The Trust will promote the investigation and shared learning from patients, clients and service users choking incidents to prevent further similar occurrences**. (Appendix 1).**

e) Safeguarding.

Ensure staff show knowledge of consent and capacity legislation and best interest processes. Establish the capacity of a patient, client or service user to be able to make a risk based decision regarding their choice of food. Where the person does not have capacity to support them to make as many decisions for themselves or to make best interest decisions in the interest of their health and safety. **(Appendix 10).**

If a person does have capacity and continues to eat preferred food and drink against advice on swallow safety, The risk feeding decision should result in a plan which balances safety and quality of life as equally as possible, taking fully into account the personal, cultural and religious beliefs of the individual. This should be documented in the patients' notes.

Ensure effective commissioning and monitoring of placements for people who have Eating, Drinking and Swallowing (EDS) difficulties or are at risk of choking.

If a parent or carer is in dispute about the choking/ dysphagia management plan and the service user is deemed to be at significant risk variance, should be fully documented and referred to the consultant and/or GP for further team discussion regarding need for safe guarding advice or referral.

In some cases, as a result of best interest discussions, a decision may be taken to limit a person's access to particular environments, within for example a residential setting in order to minimise choking risk and keep that person safe. This decision will be backed up by appropriate risk assessments. It should be recognised that if this action is taken, it may result in a deprivation of liberty which would fall under the Deprivation of Liberty Safeguards.

In such cases an exceptional care plan may be agreed by the Multi Disciplinary Team (MDT) e.g. risk feeding.

Risk Feeding

When a person continues to eat and drink despite a risk of aspiration and or choking, this is referred to as risk feeding. Risk feeding may be put in place for one or more of the following reasons:

- Advance stages of illness
- The person's swallow is not safe and is unlikely to improve
- When preferred food and drink takes priority over swallow safety
- Tube feeding options are declined or inappropriate

The risk feeding decision should result in a plan which balances safety and quality of life as equally as possible, taking fully into account the personal, cultural and religious beliefs of the individual. This should be documented in the patients' notes.

f) Prevention

The Trust will encourage the development of safe systems of work, local protocols and procedures in relation to the prevention of choking and ensure patients, clients and service users are given safe and appropriate food and drink, MDT and SLT Care Plans are followed, advice on good oral care, respiratory care, posture and seating, reflux management and medication reviews.

The Trust will help empower service users and their carers to manage risk by increasing their knowledge of high risk foods, the importance of encouraging safe eating behaviours and promoting safe eating environments.

g) Information & Training

The Trust will ensure that staff are adequately trained to support patients, clients and service users with eating, drinking and swallowing (EDS) difficulties and those at high risk of choking.

The Trust will ensure the availability, in Trust facilities, of modified foods at all mealtimes/snack times for patients, clients and service users.

The Trust will ensure staff have an awareness of available resources and sources of expert advice.

Service Areas should agree a consistent alert system to identify patients, clients and service users at high risk of choking e.g. use of alert system on Paris.

Another example of good practice is the bed side care plan (Acute Setting) or the Personal Place Mat (Community Setting). Learn more about Personalised Placemats and download of a Placemat Template, with instructions. **(Appendix 12)**

Ensure clear communication when going into hospital. An example of good practice would be promotion of Hospital Passports **(Appendix 13)**.

To adequately train staff, who support patients, clients, and service users with swallowing difficulties or at risk of choking, in eating, drinking and swallowing awareness training and to make a first aid response if a person does choke. Staff can self-assess their awareness, knowledge, skills and confidence by using the example tool at **Appendix 14.**

(Refer to **Appendix 8** - Available Training Programmes).

- Face to face eating drinking and swallowing (EDS) awareness training is available contact your local SLT Department.
- Access Eating, Drinking and Swallowing awareness eLearning - http://elearning.belfasttrust.local/course/search.php?search=eating and the choking awareness DVD from the HUB eLearning site
- The Resuscitation Council have very clear guidelines on the treatment of choking which can be accessed by clicking on the link above

- The Trust's Resuscitation Officers provide the following programmes:
  - In-hospital Life Support (Hospital Staff) – 3 hrs (Adult) 3 Hrs (Paediatrics)
  - Community Basic Life Support (Community Staff) – 2 hrs or 3 hrs (with AED)
  - Please refer the Trust's Statutory/Mandatory Matrix for further details.
- The Resuscitation Officer should be contacted in relation to arranging specialised training sessions for particular Service Areas/Patients/Service Users, incorporating Ward based scenarios.

5.0 IMPLEMENTATION OF POLICY

5.1 Dissemination

This Policy is required to be implemented by all Directorates.
All Staff, Managers and Departments with specific responsibilities are required to comply with this Policy as detailed.
If support or alternative formats are required in terms of communication in relation to the policy, this will be provided.

An Easy Read Guide has been developed in relation to this policy **(Appendix 17)**.

5.2 Resources

Choking awareness resources have been developed as part of a Personal and Public Involvement PPI project to help raise awareness of choking within adult learning disability services. A choking awareness DVD (22 minutes) is available to all staff on eLearning. You can access Eating, Drinking and Swallowing eLearning from the Hub eLearning site.

Please refer to Section 7 – Evidence Base References and Appendices 1 – 17 for further Resources.

5.3 Exceptions

There are no exceptions.

6.0 MONITORING

This Policy will be monitored by Service Areas investigating the circumstances surrounding choking incidents, in accordance with Trust Adverse Incident Reporting and Investigation Policies.

This Policy will also be monitored by the Health & Safety Team in relation to circumstances surrounding RIDDOR reportable choking incidents including the implementation of relevant of responsibilities, as detailed in this Policy.

Implementation will also be monitored through the Directorate of Nursing & User Experience who have ownership for this Policy.

7.0 EVIDENCE BASE / REFERENCES

Information Available from the Belfast Trust

- Information book to help raise awareness of choking, available from the Belfast Health & Social Care Trust Hub.
- Belfast Health & Social Care Trust choking awareness DVD (available from eLearning).
- Activities and resources are also available from the Belfast Health & Social Care Trust Awareness website - help stop choking desktop application and ios app available from: helpstopchoking.hscni.net (list of resources in **Appendix 15**).
- NI Heroes of Youth Awards

Journal References

- Guthrie, S et al (2012). Capacity to choose and refuse? A case study. Advances in mental health and intellectual disabilities, Vol. 6 No. 6, pp. 293-300,.
- Cash, S., & Shinnick, A. (October 2008). Basic life support and children with profound and multiple learning disabilities. paediatric nursing, Vol 20 No 8, pp. 38 - 39.
- Howseman, T. (November 1, 2013). Dysphagia in people with learning disabilities. Learning Disability Practice , Vol 16, No 9, pp. 14 - 22.
- Partnership, H. S.-a. (2012). Reducing the risk of choking for people with a learning disability A Multi-agency review in Hampshire.
- Fioritti, A et al (1997) Choking Incidents among Psychiatric Patients: Retrospective Analysis of Thirty-one Cases from the West Bologna Psychiatric Wards. Can J Psychiatry 1997;42:515–520

Other External References

- Patient, client, service user Safety Alert – HSC (SQSD) 6/15 – 24/2/15 – Risk of death from asphyxiation by accidental ingestion of fluid/food thickening powder.
- Dysphagia Diet Food Texture Descriptors NPSA, April 2011 - Appendix **3** - Northern Ireland Speech and Language Therapy - Swallowing Advice Dysphagia Modified Diet Advice Leaflets
- Reduce the risk of choking for people with a learning disability – A multi-agency review in Hampshire. Hampshire Safe Guarding Adults Board Multi-Agency Partnership.

- Choking Prevention Policy 2014, Surrey County Council.
- IHaL report of the reasonable adjustments in the management of dysphagia in people with learning disabilities, includes a summary of the research evidence and guidance as well as links to resources and examples from practice. Available from http://www.improvinghealthandlives.org.uk/publications
- NICE clinical guideline 76 Medicines adherence - Involving patient, client, service users in decisions about prescribed medicines and supporting adherence Issued: January 2009.
- Reducing the risk of choking for people with a Learning Disability; a multi-agency review, Hampshire Safeguarding Adults Board.
- Choosing Medicines for Patients unable to take solid oral dose forms
- Safety and Quality Reminder of Best Practice Guidance
- Management and advice for patients/clients with swallow/dysphagia problems SQR/SAI/2015/015(OPS/MH/LD/AS) HSC & PHA
- Referral protocol for inpatients requiring dental treatment or assessment at the School of Dentistry
- Resource Manual for Commissioning Services for SCLN: Dysphagia (2014) RCSLT.
- Resource Manual for Commissioning Services for SCLN: Head and Neck Cancer ("2014) RCSLT.
- Speech and Language Therapy Provision for People with Dementia – RCSLT Position Paper 2014.

8.0 CONSULTATION PROCESS

This policy has been devised in collaboration with the Trust's Health & Safety Managers, Joint Health & Safety Committee, Co-Directors and Senior Managers throughout the Trust.

Consultation with staff and their trade union representatives during development and introduction of a policy is a legal requirement and it will also help to enhance employee relations, ref: Health & Safety (Consultation with Staff) Regulations (NI) 1996 and The Safety Representatives and Safety Committee Regulations (NI) 1979.

Service users were consulted on the Easy Read Guide (Appendix 17).

9.0 APPENDICES / ATTACHMENTS

Appendices 1 - 8 are Mandatory

Appendices 9 – 17 are examples of Good Practice.

Mandatory

Appendix 1 - Immediate Actions to Consider Following A Choking Event (can also be used as a risk screening tool)
Appendix 2
- 2a – Decision Tree
- 2b - MDT Risk Assessment Form
- 2c - Completed Example Choking / Dysphagia Risk Assessment

Appendix 3 - NI Dysphagia Diet Descriptions / Advice Leaflets
Appendix 4 - Supervision Levels
Appendix 5 - Indicators For Referral To Speech & Language Therapy For Eating, Drinking & Swallowing Assessment
Appendix 6 - SLT Department Care Plan
Appendix 7 - Choosing Medicines for Patients Unable to Take Solid Oral Dose Forms
Appendix 8 - Available Training Programmes

Examples of Good Practice

Appendix 9 - Example Of Good Practice When Someone Is Highlighted As Having A Choking Risk
Appendix 10 - Choking Capacity Questions
Appendix 11 - Bedside Care Plan
Appendix 12 - Personal Place Mat Template
Appendix 13 - Hospital Passport
Appendix 14 - Choking Awareness Self-Assessment
Appendix 15 - Choking Awareness Resources from Help Stop Choking Project.
Appendix 16 - Flowchart for Reporting Choking Events
Appendix 17 – Easy Read Guide to this Policy.

10.0 EQUALITY STATEMENT

In line with duties under the equality legislation (Section 75 of the Northern Ireland Act 1998), Targeting Social Need Initiative, Disability discrimination and the Human Rights Act 1998, an initial screening exercise to ascertain if this policy should be subject to a full impact assessment has been carried out.

The outcome of the Equality screening for this policy is:

Major impact ☐

Minor impact ☐

No impact. X

SIGNATORIES

(Policy – Guidance should be signed off by the author of the policy and the identified responsible director).



_____ **Date: _____October 2017_____**

Author



_____ **Date: _____October 2017_____**

Director

Appendix 1 - Actions to Consider Following a Choking incident

This could also be used as a risk screening tool. Also refer to Appendix 16.

This form should be completed by person(s) responsible for providing direct care. Ensure you consult with the service user and gain their consent and involvement in identifying risks, also carers/ families who know the person best. It will provide a record of all actions considered following a choking incident to help prevent further choking. This information can contribute to a choking risk management plan, if needed. Please note all incidents, near misses and errors should be reported through the DATIX incident reporting system.

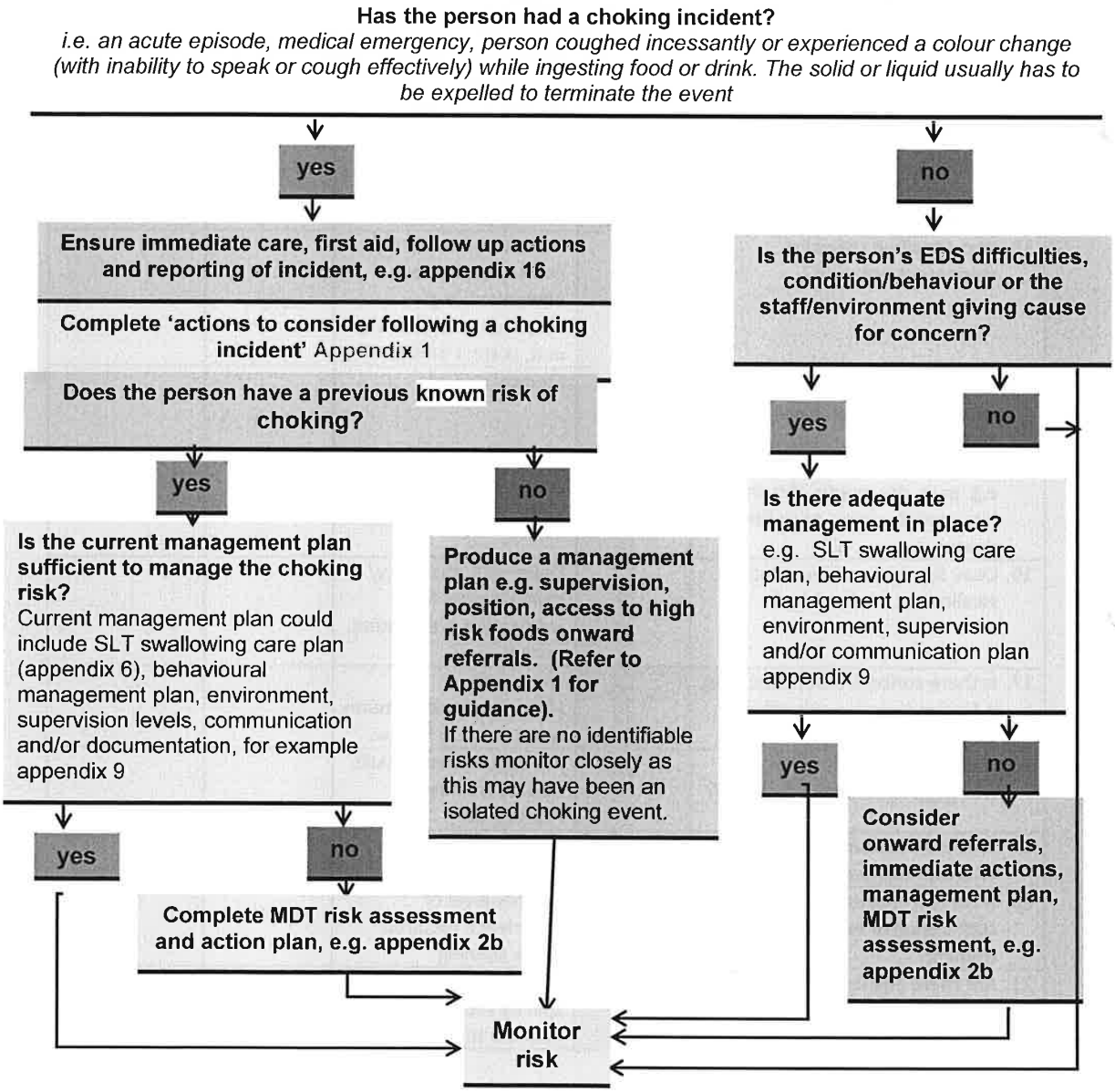
Name of patient/client			**Date of choking event**		
Date form completed			**Name of person completing form** **List all persons who contributed**		
Describe what the person was eating, the way they were eating, the environment at the time of the choke and if they cleared any blockage?			**Describe level of intervention required** Reassurance/prompt to cough/backslap/abdominal thrust/paramedic/lost consciousness/ A&E/admission. **Medical exam following incident? y/n**		
Questions to ask following a choking incident	**No**	**Yes**	**If Yes, Actions to consider**	**Completed by and date**	**Comments if no action give reason.**
1. Is there suspected aspiration of material into the lungs or a change in the person's breathing effort, rate or sounds?			Medical review Chest Physiotherapy		
2. Does any chronic respiratory condition appear worse?			GP/ Medical or Physiotherapy opinion as appropriate		
3. Is this a **new** difficulty? i.e. the person has no known choking/ Eating drinking or swallowing (**EDS**) difficulties?			Consider referral to SLT if meets referral criteria.		
4. Recent deterioration in observations of general health?			Medical review		
5. Does the person have worsening swallowing skills due to ill health?			Medical review Referral to SLT if meets referral criteria		
6. Is the person **unable** to maintain an awake alert state for duration of feed/ meal?			Ensure awake and alert before all mealtimes. Medical review.		
7. Is there concern that the EDS care plan was not applied? E.g. person choked on food that is **not** recommended?			Carers aware of EDS Care plan. Personal Place Mat in place Review access to high risk foods		
8. Did person choke on food that **is** recommended on current diet?			Avoid high risk foods Refer to SLT		

Appendix 1 Continued...

Questions to ask following a choking incident	No	Yes	If Yes, Actions to consider	Completed by and date	Comments if no action give reason.
9. Is there concern that the food preparation was inadequate? E.g. unsafe temperature, hard skin formed, texture/size?			Undertake safety checks with kitchen, food provider, and person preparing food.		
10. Does the person show unsafe eating behaviours? E.g. overfilling, fast pace, inadequate chewing, talking or moving.			Education on safe eating strategies. Consider behaviour Management plan.		
11. Is the person's ability to independently feed reduced?			Identify Support required, safe feeding guidance, PPM, bed side care plan, independent feeding assessment OT.		
12. Is the person's ability to maintain a stable and upright position throughout mealtimes reduced?			Temporary support to maintain upright stable position refer to OT for seating assessment		
13. Was specified specialist equipment **not** used?			Person had access to correct specialised equipment, e.g. dysphagia cup, non-slip mat, correct furniture?		
14. Do any oesophageal symptoms appear worse? E.g. reflux, vomiting.			Medical review		
15. Are there any oral health issues e.g. pain, dry mouth, thrush, loose teeth, caries, poor fitting dentures.			increase mouth care medical/ dental review as per protocol		
16. Does the person have difficulty swallowing medications?			Liaise with pharmacy/ medical team for medication preparation review		
17. Is there concern that medication is having negative side effects (e.g. drowsy, dry mouth)?			Liaise with pharmacy/medical team re medication review.		
18. Is there concern that first aid was **not** administered correctly?			Revise knowledge/skills Update training Practice drills		
19. Was the mealtime environment interrupted/rushed/noisy?			Protected mealtimes		
20. Is there a concern over the staff's level of experience or training?			Identify level of experience required check training		
21. Are there any staffing concerns impacting supervision?			Increase monitoring, specify supervision level Escalate to manager		

Appendix 2a - Decision Tree to help guide staff on when to complete a MDT choking risk assessment

Early identification and screening is essential to ensure that people at potential risk of choking are risk assessed, risks documented and appropriate risk management implemented including referral where appropriate. For some people increased supervision, a swallowing care plan or behavioural management plan may be sufficient to manage the risk. For a small number of people who have significant risk or are complex a highly individualised MDT choking risk assessment should be considered. This decision tree is to help guide staff on when to complete a MDT choking risk assessment **(Appendix 2b).**



A risk assessment should be completed for all patients who have a risk of a choking episode.

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Appendix 2b - V2/July2016/SLT/AC

MDT RISK ASSESSMENT FORM

CHOKING/DYSPHAGIA RISK ASSESSMENT
DATE OF RISK ASSESSMENT/REVIEW MEETING.....

Risk assessments carefully examine the person and their situation to identify factors that could cause or contribute to harm to the individual or to others. The assessment investigates whether adequate precautions are in place to prevent injury, ill health or other negative consequences, or if further measures are required.

This dysphagia risk assessment (based on the NPSA risk form 2006) seeks to answer the following questions:

- What is the current situation?
- What could go wrong?
- How serious is the harm to the person?
- How likely is the harm to occur?
- What actions are needed to prevent harm?
- How and when will the situation be reviewed?

People involved in the Risk Assessment		
Name and contact details	**Indicate type of involvement, e.g. present for meeting, consulted**	**Signature** To indicate awareness and agreement
Person with Dysphagia		
Family member/Caregiver		
Advocate		
Residential Staff		
Respite Service		
Day centre staff		
School Staff		
SLT		
Dietician		
Community nurse or School Nurse		
PT		
OT		
GP		
Other (give details)		
Notes:		

Appendix 2b Continued...

NATURE OF PROBLEM
(e.g. describe type and severity of dysphagia (refer to risk of aspiration, choking, chest infection, nutritional comprise, dehydration and other)

☐ Is this a new problem
☐ or an existing problem that has worsened

OTHER EXISTING PHYSICAL HEALTH CARE NEEDS
(Include details of current medication)

CURRENT EATING AND DRINKING SITUATION
(Where meals are taken/level of support needed etc.)

PREVIOUS HEALTH/RISK ISSUES
(Include any previous factors which could potentially affect the swallow, rapid decline in swallow safety when unwell)

Appendix 2b Continued...

ASSESSMENT OF LEVELS OF RISK

For further guidance see The NPSA *Guide to Levels of Risk of Negative Health Consequences* Dysphagia negative health consequences

Risk area	Level of Risk			Details
	Low Risk	Medium	High Risk	
INTRINSIC FACTORS				
Medical Diagnosis				
Cognitive function				
Level of alertness, Level of cooperation				
Fatigability / endurance				
Rapid decline due to ill health				
Postural control				
Oral Health				
Oral structures, motor function and sensation				
Pharyngeal structures, motor function, sensation				
Gastro-oesophageal reflux disease				
Underlying respiratory functions				
Seizure activity				
Behavioural difficulties				
Mental Health difficulties				
Medication				
Nutrition and hydration, weight				
Reliance on others for eating and drinking				

Risk area	Level of Risk			Details
	Low Risk	Medium	High Risk	
EXTRINSIC FACTORS				
Physical environment				
Social environment				
Access to eating and drinking equipment				
Staffing levels				
Patient's adherence				
Staff adherence				
Family adherence				

Appendix 2b Continued....

DYSPHAGIA RISK MANAGEMENT PLAN

What Could Go Wrong (Risk Area)	Severity Of Problem			Likelihood Of Harm Occurring			What Needs To Be Done	Agreed Actions	Named Person Responsible For Actions	TIME-SCALE (date by which action is to be completed)
	High	Med	Low	High	Med	Low				
Name, role and Signature of people agreeing to this plan (please describe any disagreements)										

Appendix 2b Continued...

CONTINGENCY PLAN:

What action will be taken if situation deteriorates?

Who will be responsible for action?

Who will be informed?

What action will be taken in the event of an emergency?

Who will be responsible for action?

Who will be informed?

Date of next meeting/review:

Adapted from the NPSA risk form 2006 Dysphagia risk assessment form

Joe Bloggs dob 11/1/11
11 Somewhere Ave,
Someplace Town BTTT 111
Paris id 23445

Belfast Health and Social Care Trust
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Appendix 2c

COMPLETED EXAMPLE CHOKING/DYSPHAGIA RISK ASSESSMENT

CHOKING/DYSPHAGIA RISK ASSESSMENT
DATE OF RISK ASSESSMENT/REVIEW MEETING.....25/3/16

Risk assessments carefully examine the person and their situation to identify factors that could cause or contribute to harm to the individual or to others. The assessment investigates whether adequate precautions are in place to prevent injury, ill health or other negative consequences, or if further measures are required.

This dysphagia risk assessment (based on the NPSA risk form 2006) seeks to answer the following questions:

- What is the current situation?
- What could go wrong?
- How serious is the harm to the person?
- How likely is the harm to occur?
- What actions are needed to prevent harm?
- How and when will the situation be reviewed?

People involved in the Risk Assessment

Name and contact details	**Indicate type of involvement, e.g. present for meeting, consulted**	**Signature** To indicate awareness and agreement
Person with Dysphagia	Person did not attend meeting but is felt to have capacity and risk management was discussed prior and after the meeting	
Family member/Caregiver Mrs Bloggs, Mother Tel 028900000	SLT discussed on the telephone prior to the meeting and after the meeting	
Advocate		
Residential Staff	Sandra Someone	
Respite Service		
Day centre staff	Tommy Somebody	
School Staff		
SLT	Amy Anyone	
Dietician		
Community nurse or School Nurse		
PT		
OT		
GP	Dr James Bond	
Other (give details)		
Notes:		

NATURE OF PROBLEM
(e.g. describe type and severity of dysphagia (refer to risk of aspiration, choking, chest infection, nutritional comprise, dehydration, other)

Joe is a 46 year old man with a medical history of learning disability, reflux and reduced mobility.
Joe has had 3 choking events which have required staff intervention including back slaps, abdominal thrusts and assessment at an emergency department. The reason for the choking is felt to be due to unsafe eating behaviours, eating at a fast pace, overfilling the mouth, eating food without a drink, swallowing without adequate chewing. Joe has had a swallowing assessment and does not have a dysphagia but has a continued risk of choking due to unsafe eating behaviours. There is no history of chest infections or concerns about weight or hydration.

Non-compliant with SLT recommendations. Joe agreed to trial a texture E fork mashable dysphagia diet and have his food cut up to 1.5cm. Following the trial he choose to return to a normal diet and does not want to have his food cut up.

☐ ✓ Is this a new problem
☐ or an existing problem that has worsened

OTHER EXISTING PHYSICAL HEALTH CARE NEEDS
(Include details of current medication)

Joe is a 46 year old man with a medical history of learning disability, reflux and reduced mobility. Currently taking Omeprazole for gastroesophageal reflux disease (GERD)
Requires support with personal care.

CURRENT EATING AND DRINKING SITUATION
(Where meals are taken/level of support needed etc.)

Currently eats within dining room with general supervision, support to carry food and drink to table. Occasionally positions self out of view and eats unsupervised.

PREVIOUS HEALTH/RISK ISSUES
(Include any previous factors which could potentially affect the swallow, rapid decline in swallow safety when unwell)

No other known health risks

Appendix 2c Continued...

ASSESSMENT OF LEVELS OF RISK

For further guidance see The NPSA *Guide to Levels of Risk of Negative Health Consequences* Dysphagia negative health consequences

Risk area	Level of Risk			Details
	Low Risk	Medium	High Risk	
INTRINSIC FACTORS				
Medical Diagnosis	✓			
Cognitive function	✓			
Level of alertness, Level of cooperation	✓			
Fatigability/ Endurance	✓			
Rapid decline due to ill health	✓			
Postural control	✓			
Oral Health	✓			
Oral structures, motor function and sensation	✓			
Pharyngeal structures, motor function, sensation	✓			
Gastro-oesophageal reflux disease		✓		Long term reflux
Underlying respiratory functions	✓			
Seizure activity	✓			
Behavioural difficulties	✓			
Mental Health difficulties	✓			
Medication	✓			
Nutrition and hydration, weight	✓			
Reliance on others for eating and drinking	✓			

Risk area	Level of Risk			Details
	Low Risk	Medium	High Risk	
EXTRINSIC FACTORS				
Physical environment		✓		Can at times position self out of site
Social environment		✓		Attention to task can be reduced if increased noise activity
Access to eating and drinking equipment	✓			
Staffing levels	✓			
Patient's adherence			✓	Refuses texture E diet, does not want to have high risk foods modified or removed, e.g. food cut up
Staff adherence	✓			
Family adherence	✓			

Appendix 2c Continued...

DYSPHAGIA RISK MANAGEMENT PLAN

What Could Go Wrong (Risk Area)	Severity Of Problem			Likelihood Of Harm Occurring			What Needs To Be Done	Agreed Actions	Named Person Responsible For Actions	TIME-SCALE (date by which action is to be completed)
	High	Med	Low	High	Med	Low				
Choke while eating		✓		✓			Ensure all staff are aware of choking risk, safe food choices and the safe eating strategies.	Create Personal Place Mat to remind staff of the choking risk.	Tommy Somebody	May 16
							Increase Joe's choking awareness, high risk foods and safe eating strategies.	Provide choking awareness sessions	Amy Anyone	May 16
							Ensure staff have update first aid training, swallowing awareness and choking awarness.	Check training record	Manager of day service	Annually May 16
							Ensure general supervision level, i.e. designated staff/carer remains within the immediate dining area observing at all times.	Ensure adequate staffing levels	Manager of day service	Continuous
							Agree safe mealtime management	All staff supporting mealtimes will Encourage a texture E fork mashable diet. Offer to cut up difficult foods.	Tommy somebody	May 16
Name, role and Signature of people agreeing to this plan (please describe any disagreements) Sandra someone, Tommy Somebody, DR James Bond, Amy Anyone										

Appendix 2c Continued...

CONTINGENCY PLAN:

What action will be taken is situation deteriorates?
If there is a further choking event revise choking awareness and relook at risk management plan

Who will be responsible for action?
Tommy somebody

Who will be informed?
Amy Anyone Manager of day services and Dr James Bond

What action will be taken in the event of an emergency?
Remove food, choking first aid

Who will be responsible for action?

All

Who will be informed?
Follow choking policy guidance

Date of next meeting/review:

Appendix 3 - Northern Ireland Speech and Language Therapy Swallowing Advice Dysphagia Modified Diet Advice Leaflets

http://elearning.belfasttrust.local/pluginfile.php/24566/mod_resource/content/3/Dysphagia Modified Diet Advice Leaflets.pdf

Texture B Thin puree
http://elearning.belfasttrust.local/pluginfile.php/24560/mod_resource/content/3/Dysphagia%20-%20Swallowing%20Advice%20B%20Thin%20Puree.pdf

Texture C Thick puree
http://elearning.belfasttrust.local/pluginfile.php/24561/mod_resource/content/5/Dysphagia%20-%20Swallowing%20Advice%20C%20Thick%20Puree.pdf

Texture D Pre mashed
http://elearning.belfasttrust.local/pluginfile.php/24562/mod_resource/content/4/Dysphagia%20-%20Swallowing%20Advice%20D%20Moist%20Mashed.pdf

Texture E Fork mashable
http://elearning.belfasttrust.local/pluginfile.php/24563/mod_resource/content/3/Dysphagia%20-%20Swallowing%20Advice%20E%20SoftFork.pdf

Swallowing Advice Dysphagia Diet - TEXTURE BREAD

Swallowing Advice - Thickened Drinks

Paediatric Swallowing Advice: TEXTURE A Liquid Puree

Paediatric Swallowing Advice: TEXTURE B Thin Puree

Paediatric Swallowing Advice: TEXTURE C Thick Puree

Paediatric Swallowing Advice: TEXTURE D Pre-mashed (moist-mashed)

Paediatric Swallowing Advice: TEXTURE E Fork Mashable (soft)

Paediatric Swallowing A dvice: THICKENED DRINKS

Appendix 4 - Supervision

The following supervision descriptions are guidance only and may be subject to change depending on changes in client's medical condition, behaviour, level of alertness, fatigue, familiarity with the environment and staff etc.

Supervision descriptions are based solely on the SLT's opinion of staff/carer supervision required to adhere to recommendations made by SLT following eating, drinking and swallowing assessment.

Supervision descriptions around eating and drinking and swallowing only reflect supervision required to eat and drink FOOD ITEMS safely without causing the client to choke, aspirate, become malnourished or dehydrate and do not take into account other environmental or behavioural issues which may also cause safety issues around mealtimes.

Independent
Description:
No supervision required.

Example
There are currently no clinical indicators that supervision is required.

General Supervision
Description:
Designated staff/carer remains within the immediate dining area while clients are eating and drinking, observing at all times. The staff member would be responsible for ensuring their familiarity with the SLT Eating, drinking and swallowing recommendations of clients as appropriate including provision of food and fluids according to the recommended textures.

Examples:
- Can eat/drink independently
- Risk of choking may be increased due to environmental factors/distractions
    - ➢ General monitoring for any signs of difficulty/aspiration and action to provide assistance if required.

Direct supervision
Description:
Staff/carer supervises/assists a small number/group of clients while eating and drinking. This supervision may be used to provide verbal prompting regarding (staff need to be observing clients directly at all times)
- Rate of eating and drinking
- Volumes of food or fluid taken
- Use of correct utensils

Appendix 4 Continued.....

Examples:
- Client may require verbal prompts/assistance
- To promote independence in eating/drinking
- To chew and swallow
- Reduce distractions in environment

  - ➢ Choking risk identified
  - ➢ Client needs to be monitored for signs of difficulty/aspiration

<u>One-to-one supervision/support</u>
Description:
Staff/carer provides full assistance/direct one- to- one support/supervision to an individual client while eating and drinking.
This will apply to people who require physical prompts/assistance, hand over hand feeding, support, monitoring and direction re eating and drinking recommendations at all times.

Examples: Client may require verbal and physical prompts/assistance due to
- Poor hand to mouth co-ordination
- Overloading spoon/cramming food
- Poor self-awareness of choking risk

They may require assistance to:

- Alternate food/fluids
- Control rate and volumes of intake
- Ensure adequate clearance of food and fluids/ prompt multiple swallows
- Use swallowing techniques and strategies
- Stop eating or drinking if there are signs of fatigue

  - ➢ Choking risk identified
  - ➢ Client needs to be closely monitored for signs and symptoms of aspiration

It is recommended that all staff with responsibility for providing supervision of clients eating, drinking and swallowing should have received swallowing awareness training.

Additional Notes:
It is acknowledged that some people particularly within ALD settings may not fit neatly into these descriptions of supervision, e.g. clients with behaviours that challenge/ autism. Some of these clients may have difficulty tolerating the presence of a staff member in their immediate environment supervising their eating and drinking but nevertheless require some monitoring. In these instances the SLT will provide specific guidance regarding supervision/ support within the individual's bespoke recommendations.

Supervision descriptions based on the Northern Ireland SLT SQAT April 2016

Appendix 5 - Indicators for Referral to Speech & Language Therapy (SLT) for Eating, Drinking & Swallowing

- Coughing/choking during or after food and/or drink
- Recurrent chest infections or pneumonia.
- Reduction in oral intake leading to weight loss or dehydration with suspected link to swallowing problems.
- Wet or gurgly voice or breath sounds after swallowing.
- Food sticking in the mouth/throat.
- Person complaining of difficulty swallowing.
- Person displaying change in breathing pattern associated with eating or drinking, such as wheezing, breathlessness or increased congestion.
- Change in colour after eating/drinking.
- Inability to control food or saliva in the mouth.
- Increased time to chew food and initiate a swallow.
- Nasal regurgitation (food coming down nose) or reflux can be associated with grimacing or sneezing during eating or drinking.
- Prohibiting/absent oral or pharyngeal reflexes e.g. suck-swallow or bite reflexes.
- Delayed weaning (in children only) in the presence of other factors listed above.

REFERRALS THAT WILL NOT BE ACCEPTED BY SLT

When a person:

- Is stable on previous SLT advice and there has been no change since their last assessment **or** are managing their current diet with no difficulties and not wanting/requiring an upgrade, however where staff are concerned, patients should be re-referred.
- Are currently too medically unfit to eat and drink, please refer when condition improves.
- Have confirmed or suspected oesophageal difficulties with no oral pharyngeal difficulties reported.
- Are refusing **all** food and drink so their swallow cannot be assessed at this time. Please seek medical advice and re-refer when they start to eat or drink if they continue to have difficulties.
- Are having difficulty swallowing medication only, seek advice from pharmacy.

Appendix 5 Continued...

When a child:

- has difficulty with use or progression of feeding utensils.
- is a selective eater.
- overpacks their mouth
- has a normal developmental weaning pattern such as initial resistance to cup drinking or lumpy foods

*If appropriate, please first check that the person is following the Speech and Language Therapists' previous recommendations. If the person has been following the previous advice and you notice any of the above signs, please contact the relevant Speech & Language Therapy Department to discuss further.

Client Details Label

Belfast Health and Social Care Trust
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Speech and Language Therapy Department

SWALLOWING CARE PLAN

The following recommendations have been made to reduce the risk of chest infections/choking when eating and drinking.

SPEECH AND LANGUAGE THERAPIST: _____ Tel: _____

_____

SUPERVISION

□ One-to-one supervision/support

□ Direct supervision
(supervise/assist a small number of clients)

□ General Supervision
(Designated staff remains within the immediate area)

□ Independent

ASSISTANCE

- ☐ Support to sit upright
- ☐ Hand-over-hand support
- ☐ Check mouth is clear after eating
- ☐ Encourage person to alternate food with liquids
- ☐ Quiet focused mealtime, no talking or moving while eating
- ☐ Prompting to slow down
- ☐ Encourage small mouthfuls

LIQUIDS

- ☐ NORMAL THIN LIQUIDS
- ☐ SYRUP CONSISTENCY STAGE 1
  Consistency of double cream, can be drunk from a cup
- ☐ CUSTARD CONSISTENCY STAGE 2
  Consistency of tinned custard, can be drunk from a cup
- ☐ PUDDING CONSISTENCY STAGE 3
  Consistency of jam/mousse, needs to be taken with a spoon

Ensure adequate storage arrangements of thickening agents to prevent accidental eating

FOOD

- ☐ NORMAL
- ☐ SOFT/FORK MASHABLE – TEXTURE E
- ☐ MOIST/MASHED/PRE-MASHED – TEXTURE D
- ☐ THICK PUREE – TEXTURE C
- ☐ THIN PUREE – TEXTURE B
- ☐ BREAD YES / NO

Following these recommendations can help reduce but not remove the risk of chest infections or choking.
THIS CARE PLAN REPLACES ANY PREVIOUS CARE PLANS PROVIDED.

Specific instructions/specialised equipment

Monitor chest status closely for any signs of deterioration – please see overleaf.

If you are concerned regarding this person's ability to manage these recommendations or require further information please contact the Speech and Language Therapy Department on the above telephone number.

DISCUSSED AND AGREED WITH PATIENT ☐ CARERS ☐ CARE STAFF ☐ FAMILY ☐
DETAIL ADVICE LEAFLETS PROVIDED ☐ _____
REFER ON TO ☐ _____
DATE OF NEXT REVIEW/DISCHARGE _____ Signed _____ Date
COPIES OF CARE PLAN PROVIDED TO PATIENT ☐ FAMILY ☐ NH ☐ SW ☐ Day care ☐ OTHER_____

Client Details Label

Belfast Health and Social Care Trust
caring supporting improving together

Appendix 6 Continued...

GUIDANCE FOR CARERS OF PATIENTS WITH SWALLOWING DIFFICULTIES

The following may indicate deterioration in a person's swallowing ability and a reassessment by Speech & Language Therapy may be required.

- Coughing/choking during or after food and/or drink
- Recurrent chest infections, or pneumonia
- Reduction in oral intake leading to weight loss or dehydration with suspected link to swallowing problems.
- Wet or gurgly voice/breath sounds after swallowing.
- Food sticking in the mouth/throat.
- Person complaining of difficulty swallowing.
- Person displaying change in breathing pattern associated with eating or drinking, such as wheezing, breathlessness or increased congestion.
- Change in colour after eating/drinking.
- Inability to control food or saliva in the mouth.
- Increased time to chew food and initiate a swallow.
- Nasal regurgitation (food coming down nose)

*Please first check that the person is following the Speech and Language Therapist's previous recommendations. If they **have** been following the advice and you notice any of the above signs, please contact the relevant Speech & Language Therapy Department to discuss further.

If the patient is still in hospital, please contact the Hospital Speech & Language Therapy Department.

If the patient is in community please contact the Community Adult Speech & Language Therapy Team or re-refer through Call Management.

Knockbreda Well Being & Treatment Centre (South & East Belfast area) Tel: **028 9504 2324.**
Call Management: 90565565.

Shankill Well Being & Treatment Centre (North & West Belfast area) Tel: **95040330**
Call Management: 02890635300/0845 6066596

CPSampleAug16.cd

Appendix 7 - Choosing Medicines for Patients Unable to Take Solid Oral Dose Forms

http://niformulary.hscni.net/Formulary/Adult/specials/Pages/default.aspx

Appendix 8 - Available Training Programmes

Eating Drinking and Swallowing (EDS) Training Requirements Matrix

Please note this is a guideline agreed by BHSCT SLT, as knowledge, skills and competencies of staff vary greatly.

Informal EDS training – discussion and demonstration of care plan
Informal training takes places with individuals and people involved in their care to ensure understanding of individual care plans; this may include staff, carers and family.

***Staff accessing level 2 training do not need to access level 1 training first.**

Level one - EDS eLearning (45minutes recommended frequency - repeat every 2 years)
Level one training is to promote awareness of swallowing and the risks associated with EDS difficulties. To help staff identify people who may have difficulties and ensure appropriate onward referral.

- Recommended for all staff who work directly with or prepare food for people.
- Appropriate for managers and MDT members who make referrals to SLT.
- Useful for staff who have previously attended level 2 training but feel they would benefit from a revision to help build confidence, i.e. following an EDS incident.
- Also benefits new staff who require awareness while they await level 2 training.

Click link to access Eating, Drinking and Swallowing eLearning or visit the hub eLearning. The 'Help Stop Choking' choking awareness DVD is also available from this eLearning site and from the choking awareness website http://helpstopchoking.hscni.net/

Level 2 - Direct EDS Awareness Training (Recommended frequency - every 3 years).
Level 2 direct EDS Acute/inpatient 1hour
Level 2 direct community/schools 3.5hours

- Recommended for staff who work directly with or prepare food for people who may have, or be at risk of developing, EDS difficulties.

As well as promoting awareness of EDS, the risks associated with EDS difficulties, how to identify people with EDS difficulties and ensure appropriate onward referral this level of training also helps to increase confidence in feeding people with EDS, using thickeners and modified diets and support staff to share their own experiences.

Level 2 direct EDS Acute/inpatient 1hour – includes demonstration of how to thicken drinks and some limited discussions. Recommended for staff working in acute and inpatient wards with people who have EDS difficulties and have onsite access to SLT for ongoing demonstration and support.

Level 2 direct community/schools 3.5hours - includes discussions and practical experience of how to thicken drinks and feed others. Recommended for staff and carers in the community and schools who support/feed people with confirmed EDS difficulties.

There is rolling level 2 training available, within existing resources, for more information contact your local SLT department.

Guidance on Choking from the Belfast Trust Resuscitation Team

The Resuscitation Council (UK) does not comment on the care of specific individuals and final decisions regarding which treatments are appropriate rest with the multidisciplinary team responsible for care.

General advice for a wheelchair user who is choking:

- This will be individual to the person involved.
- If possible the person choking should be encouraged to cough.
- If this is ineffective the manoeuvre/s used will depend on the individual, the rescuer(s) and the ability of the rescuer(s) to position themselves to undertake the manoeuvre. The general advice would be to undertake backslaps and/or abdominal thrusts if these are possible within the confines of the chair.
- Call for help early as a second or more rescuers can help support the person choking during back slaps or abdominal thrusts.
- If the person becomes unconscious they would need to be laid on a firm surface (floor) and CPR started.

This is what we would teach at present.

The Resuscitation Training Team recommend that if the patient has a severe & multiple Learning Disabilities, the Team looking after that patient will need to contact their medical physician for advice.
Each individual case will have different needs i.e. displacement of heart/lungs, ribs, no sternum which only their doctor may be aware off.

The Resuscitation Team will continue to teach RCUK guidance for choking on our mandatory training sessions"

The Resuscitation Council have very clear guidelines on the treatment of choking which can be accessed by clicking on the following link http://www.resus.org.uk/

The Trust's Resuscitation Officers provide the following programmes:

- In-hospital Life Support (Hospital Staff) – 3 hrs (Adult) 3 Hrs (Paediatrics)
- Community Basic Life Support (Community Staff) – 2 hrs or 3 hrs (with AED)

Please refer the Trust's Statutory/Mandatory Matrix for further details.

The relevant Resuscitation Officer should be contacted in relation to arranging specialised training sessions for particular Service Areas/Patients/Service Users, incorporating Ward based scenarios.

Trust's First Aid Training Policy

The Trust's 3 day First Aid course and 1 day Emergency First Aid course also contains a section on administering first aid to a person who is choking.

Please note that the First Aid at Work Regulations (NI) 1982 make first aid provision for staff who are injured or become ill at work. Link to First Aid Policy below : First Aid at Work Policy

Appendix 9 - Example Of Good Practice When Someone Is Highlighted As Having A Choking Risk

1. Admission assessment contains trigger question on history of choking e.g. NAPOC, NISAT, About You.

2. Person is highlighted during admission assessment that they have a choking risk.

3. Staff investigate further to gain as much information as possible on past events, swallowing assessments, possible triggers, recommendations etc. and consider referral to relevant members of MDT.

4. This information is then passed on to all staff via communication board and all high risks are discussed at handover.

5. Information is passed to the Catering or Food Provider via phone call or speaking to the cook personally.

6. Risk identified on the menus for the person in question.

7. Person's risk is highlighted on the menu boards with a star.

8. Personal Place Mats or Bedside Swallowing Care Plans are used to highlight choking risk at mealtimes.

9. If a patient is identified as a very high risk then they will be placed on a level of supervision at meals times. A plan of care will be placed in the nursing care plan for all staff to read. This is reviewed a regular intervals or upon need.

10. If there is any change all above is reviewed and amended.

Appendix 10 - Choking Capacity Questions

This tool outlines information that an individual or their carer needs to understand and retain in relation to the risk of choking. It can be completed as a record of someone's understanding in relation to choking, to support capacity assessments and help with management of non-compliance. *(Developed by Helen Cunliffe, Principal Speech & Language Therapist, September 2014).*

	Key concepts
What does the word 'choking' mean?	*(e.g. blockage, food gets stuck in the throat)*
What happens when you choke?	*(e.g. something gets stuck, stops you breathing, you could die)*
What will happen if you stop breathing?	*(e.g. could die, could cause other injury)*
What do you think caused your choking episode(s?)	*(e.g. check for understanding e.g. of any underlying condition)*
Do you think there's a chance that you could choke again?	*(e.g. check for understanding of any potential contributory factors.)*
Can you think of things that might make you choke?	*(e.g. high risk foods for choking, unsafe eating behaviours see also factors which can increase the risk of choking)*
What would you do if you started to choke?	*(e.g. stop eating/call for help)*
What if you are choking and not able to speak or call for help?	(e.g. Lifeline)
What can you do to avoid another choking episode? *(Any visual/written resources required as prompts?)*	*(e.g.) cut food up smaller next time)*

Appendix 11 - Example Bedside Care Plan
PLEASE CHECK FOR LOCAL ARRANGEMENTS

SWALLOWING RECOMMENDATIONS
Speech and Language Therapy

NAME: _____ DATE: _____

FEEDING ADVICE	• Alert and upright • Monitor chest status • Discontinue feeding if any signs of aspiration (coughing/choking/throat clearing/"wet" voice or "wet" breath sounds/pallor change/reduced O2 sats/reduced chest status, etc.) • Regular mouthcare / oral hygiene
LIQUIDS Stage ☐	
DIET Texture ☐	
SUPERVISION	
MEDICATION	

If you have any concerns regarding the above, please contact the Speech & Language Therapist on the number below.

Signature: _____

Speech and Language Therapist

Appendix 12 - Personal Place Mat

Click here to Learn more about Personalised Placemats and download of a Placemat Template, with instructions.

http://www.communicationpassports.org.uk/Creating-Passports/Templates/?print=yes

Appendix 13 - Link to Hospital Passport

http://intranet.belfasttrust.local/Documents/Hospital-Passport-BHSCT.pdf

http://www.publichealth.hscni.net/publications/hsc-hospital-passport

http://www.publichealth.hscni.net/publications/guidance-notes-your-hsc-hospital-passport

Appendix 14 - Choking Awareness - Staff Self-Assessment

Use this form to reflect and rate your awareness, knowledge, skills and confidence in identifying people who may have a choking risk and managing that risk. If you score 30, or below, please revise knowledge, e.g. watch the choking awareness DVD available from the eating, drinking and swallowing eLearning. A copy of your completed form can be provided to your manager as evidence of your choking awareness following choking incidents.

Name _____ **Date** _____

Score your awareness, knowledge, skills and confidence from 5 very good to 1 very poor.

	5 Very good I know everything	4 Good I know most things	3 Ok I know some things	2 Poor I know a little	1 Very poor I know very little
1. Do you know what choking is and why people choke?					
2. How would you rate your ability to recognise the signs when someone is choking?					
3. How would you rate your knowledge of the consequences and risks of choking?					
4. How would you rate your knowledge of which foods are high risk choking foods?					
5. How would you rate your skills of knowing how to modify/change food to make it easier to eat?					
6. How would you rate your knowledge of safe eating strategies?					
7. How would you rate your skills of making the environment safer to reduce the risk of choking?					
8. How would you rate your knowledge of the different people who can help someone who has a choking risk?					
9. Are you confident in how to help someone who is choking in an emergency?					
10. Are you confident you know how to support a person who chooses to eat high risk foods?					

Total score /50

Appendix 15 - Help Stop Choking - Choking Awareness Resources

Help reduce the risk of choking by using The Help Stop Choking Website which offers a series of accessible DVD clips, activities, advice leaflets, posters and recording forms available to download for free http://helpstopchoking.hscni.net

Also available as an app for apple devices which allows you to work offline, you can meet the person where they are, no need to take them to a computer, ios app Help Stop Choking

Co-developed by BHSCT SLT team with a man with a man who has learning disability, following his own choking experience, the resources aim to empower people to increase their knowledge of choking, safe food choice, eating behaviours and eating environments, first aid and good oral care.

The original choking awareness DVD was Winner of the national Patient Safety and Care Awards 2014 and is available from the BHSCT Eating and Drinking eLearning site and the clips are available to watch from the trust YouTube.

DVD clips include

What is choking?
Change what you eat - make safe food choices
Change the way you eat - encouraging safe eating strategies
Change where you eat – promote safe eating environments,
First aid
The 'Help Stop Choking' awareness song

Choking Advice Leaflets

- *Choking awareness book – easy read*
- *How to reduce the risk of choking - General advice to help someone eat safely and reduce their risk of choking*
- *General advice for feeding a person with a choking risk*
- *Choking awareness Looking after your lungs - Useful information and top tips*
- *Choking awareness Oral health information for carers*
- *How to reduce the risk of choking General advice to help someone take medications when they have a choking risk*
- *What to do when a wheelchair user is choking*
- *Best interest decision – Easy Read*
- *Capacity and consent – easy Read*

Choking awareness posters

- *High risk choking foods*
- *First aid for choking*
- *Good ideas for a safe room*
- *Good ideas to keep mouth clean*
- *Good ideas to slow down*
- *Good ideas to stop choking*

Appendix 16 - Flowchart For follow-up actions and Reporting Following Choking incident

CHOKING INCIDENT
1. Check person treated by appropriate first-aid and follow up medical examination.
2. Inform NOK, GP and other appropriate agencies as necessary
3. Report incident via DATIX Trust internal incident reporting system; the incident may be subsequently reported under RIDDOR for the Health & Safety Executive for NI
4. Complete - Immediate Actions to Consider Following A Choking Event (**Appendix 1).**
5. Consider referral to SLT for a swallowing assessment using indicators **(Appendix 5)**
6. Complete or review care plan and risk assessment - insure controlled measures are in place. Use locally agreed risk form, Trust risk form or **Appendix 2**
7. Discuss episode among staff group and encourage shared learning
8. If care plan has not been followed and were applicable referral to be made to safeguarding in conjunction with your line manager
9. Review staff training (**Appendix 8**)
10. If applicable report to RQIA in conjunction with your line manager
11. Where appropriate consider other people within you care who may be at risk

Appendix 17

The Prevention & Management of Patient, Client and Service Users with Identified Choking Risks June 2016 - Easy Read Document

http://intranet.belfasttrust.local/directorates/medical/riskgovernance/Documents/Choking%20Policy%20Easy%20Read%20Summary.pdf

Belfast Health and Social Care Trust
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Reference No: SG 06/19

Title:	**Guideline for the translation from National texture descriptors to International dysphagia diet standardised levels**		
Author(s)	Cathy Jordan, Head of service, Speech and Language Therapy Lucy Hull, Head of service, Nutrition and Dietetics		
Ownership:	Bernie Owens, Director of Unscheduled and Acute Care		
Approval by:	BHSCT Multidisciplinary IDDSI Implementation Group Standards and Guidelines Committee Trust Policy Committee Executive Team Meeting	**Approval date:**	February 2019 07/03/2019
Operational Date:	March 2019	**Next Review:**	September 2019
Version No.	1	**Supercedes**	None
Key words:	Dysphagia, swallowing difficulty, texture descriptors, IDDSI, translation		
Links to other policies	SG 27/17 The Prevention and management of patients, clienets and service users with identified choking risks		

Date	Version	Author	Comments
01/02/2019	0.1	Cathy Jordan	Initial draft.
19/02/2019	0.2	Cathy Jordan	Amendments following feedback from IDDSI implementation group, divisional nurse and divisional social worker.

1.0 INTRODUCTION / PURPOSE OF POLICY

1.1 Background

Dysphagia is the medical term for swallowing difficulties and a sign or symptom of disease, which may be neurological, muscular, physiological or structural. Dysphagia affects people of all ages in all types of care setting. Food texture modification is widely accepted as a way to manage dysphagia.

In 2012 UK texture descriptors were published and these have been used since then
across NI. Descriptors for food and fluid textures are now changing in line with the new International Dysphagia Diet Descriptors Standardisation Initiative (IDDSI).

IDDSI is an evidence based framework developed by experts to:
- Standardise the names and descriptors of texture modified foods and thickened
liquid;
- Use numbers and colour codes to create common terminology that can be used
across cultures and by all stakeholders;
- Provide valid and practical testing methods for all levels of food and drink

In the UK manufacturers will be changing their labelling and instructions accordingly, and aim to complete this by April 2019.

Transition from the current range of food and drink texture descriptors to IDDSI framework for people with dysphagia needs careful local planning to ensure it happens as soon and as safely as possible.

An alert was issued by NHS Improvement NHS/PSA/RE/2018/004 ‘resources to support safer modification of food and drink ‘. This was followed by a DOH circular issued by Dept of health in July 2018, and a letter to Trusts in August 2018 both of which set out clear expectations form the Trust to deliver the transition to the IDDSI terminology.

Within the BHSCT a Multidisciplinary Implementation group was set up in Sept 2018 and an action plan has been put in place to manage the transition from the previous UK national texture descriptors to the IDDSI terminology

The action plan includes :

- Awareness Raising and Training for BHSCT Staff , Service Users and Carers and other relevant Stakeholders
- Local Communications Strategy re IDDSI implementation

- Update to all BHSCT resources, guidelines, policies and protocols which have reference to NPSA Dysphagia Diet Descriptors and planned update to change to IDDSI terminology by 31st March 2019.

The planned dates for ' Go live/ in BHSCT is the 11th March 2019.
From this date

- all new SLT care plans will be written using IDDSI terminology
- all dysphagia thickening products on acute sites will change to IDDSI terminology.

Translation of care plans for existing patients will be scheduled as soon as possible after the 11th March 2019.

1.2 Purpose

One of the areas that required multidisciplinary work is the transition to new Care plans and the translation of the UK National texture descriptors on old care plans to the new IDDSI terminology.

This guideline aims to set out this process for within the multidisciplinary context.

1.3 Objectives

- To give a clear process for multidisciplinary staff in the translation of the texture descriptors on current care plans to IDDSI Terminology

- To support staff in the implementation of the Transition to new Care plans and the translation of the texture descriptors on old care plans to the new IDDSI terminology

- To place this work within the Trust assurance framework

2.0 SCOPE OF THE POLICY

This guideline applies across the BHSCT for staff managing patients with Dysphagia who require a new care plan or a translated care plan as part of the IDDSI implementation process

3.0 ROLES/RESPONSIBILITIES

The process and responsibilities are outlined in 'Process for transfer to new IDDSI care plans or translation of current swallowing recommendations care plans into IDDSI terminology for all patients (Adults and Children) doc (Appendix 1)

4.0 KEY POLICY PRINCIPLES

4.1 Definitions

4.2 Key Policy Statement(s)

4.3 Policy Principles

There are 4 identified groupings of Patients

4.3.1 For new referrals for a Speech and language assessment in regard to dysphagia on or after 11th March 2019.

4.3.2 Patients (adults and Children) who are currently open cases for SLT service.

4.3.3 Patients who are on a dysphagia care plan but are closed to the SLT service. These patienets are usually within community settings.

4..3.4 Patients not known to any Trust service eg client in own homes (these could be patients who have moved into the Trust area or Patients who have been discharged from all Trust services

Process for the transition to new IDDSI terminology for these 4 groupings are outlined in (Appendix 1 and Appendix 2)

5.0 IMPLEMENTATION OF POLICY

5.1 Dissemination

This process is relevant to all Trust staff who are supporting patients adults and children who have been advised to modify their the textures in their diets due to a a swallowing difficulty (dysphagia)

This will be disseminated through the standards and guidelines committee and the BHSCT IDDSI implementation group.
Process will commence on the 11th March 2019 and will aim to be completed by end May 2019

This will be monitored through the BHSCT IDDSI implementation group.

5.2 Resources

Training has been provided through the IDDSI implementation action plan, and relevant documentation for the process will be provided.
This should include training, awareness raising, testing of new documentation associated with the policy etc and who is responsible for this.

5.3 Exceptions

Individuals where translation of current swallowing recommendations care plans into IDDSI terminology for specific patients has already taken place within the IDDSI training process.

6.0 MONITORING

The implementation of this guideline will be monitored through the BHSCT IDDSI implementation group

7.0 EVIDENCE BASE / REFERENCES

IDDSI UK – www.iddsi.uk
IDDSI translation diagram has been adapted with the permission from the IDDSI initiative and was agreed by the NI regional IDDSI implementation group.

8.0 CONSULTATION PROCESS

Consultation has taken place with the members of the BHSCT IDDSI implementation group

9.0 APPENDICES / ATTACHMENTS

Appendix 1 Process for transfer to new IDDSI care plans or translation of old care plans into IDDSI terminology for all patients (adults and children)
Appendix 2 IDDSI translation statement

10.0 EQUALITY STATEMENT

The Trust has legal responsibilities in terms of equality (Section 75 of the Northern Ireland Act 1998), disability discrimination and human rights to undertake a screening exercise to ascertain if this policy/proposal has potential impact and if it should be subject to a full impact assessment. This process is the responsibility of the policy or service lead - the template and guidance are available on the Belfast Trust Intranet. Colleagues in Equality and Planning can provide assistance or support.
The outcome of the Equality screening for this policy is:

Major impact ☐

Minor impact ☐

No impact ☒

11.0 DATA PROTECTION IMPACT ASSESSMENT

New activities that involve collecting and using personal data can result in privacy risks. In line with requirements of the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 the Trust has to consider the impacts on the privacy of individuals and ways to mitigate against the risks. Where relevant an initial screening exercise should be carried out to ascertain if this policy should be subject to a full impact assessment (see Appendix 7). The guidance for conducting a Data Protection Impact Assessments (DPIA) can be found via this **link.**
The outcome of the DPIA screening for this policy is:

Not necessary – no personal data involved ☐

A full data protection impact assessment is required ☐

A full data protection impact assessment is not required ☐

If a full impact assessment is required the author (Project Manager or lead person) should go ahead and begin the process. Colleagues in the Information Governance Team will provide assistance where necessary.

12.0 RURAL IMPACT ASSESSMENTS

From June 2018 the Trust has a legal responsibility to have due regard to rural needs when developing, adopting, implementing or revising policies, strategies and plans, and when designing and delivering public services.
It is your responsibility as policy or service lead to consider the impact of your proposal on people in rural areas – you will need to refer to the shortened rural needs assessment template and summary guidance on the Belfast Trust Intranet. Each Directorate/Division has a Rural Needs Champion who can provide support/assistance in this regard if necessary.

13.0 REASONABLE ADJUSTMENTS ASSESSMENT

Under the Disability Discrimination Act 1995 (as amended), the Trust has a duty to make reasonable adjustments to ensure any barriers disabled people face in gaining and remaining in employment and in accessing and using goods and services are removed or reduced. It is therefore recommended the policy explicitly references “reasonable adjustments will be considered for people who are disabled - whether as service users, visitors or employees.

SIGNATORIES

(Policy – Guidance should be signed off by the author of the policy and the identified responsible Director).

C.A. Jordan

26/02/2019

Authors **Date:**

B.M. Owens.

26/02/2019

Director **Date:**

Belfast Health and Social Care Trust
caring supporting improving together

Reference No: TP 106/17

Title:	**The Prevention and Management of Patient, Client, Service Users with Identified Choking Risks**			
Author(s)	Karen Cunningham, Lead Health and Safety Manager, Karen Devenney, Senior Manager Nursing, Governance and Patient, Client, Service User Safety, Nursing and User Experience Catherine Donnelly, Assistant Speech and Language Manager Adult Community Services Angela Crocker, Lead Clinical Speech and Language Therapist, In conjunction with members of BHSCT Choking Group			
Ownership:	Brenda Creaney, Executive Director of Nursing & User Experience Dr Cathy Jack, Medical Director			
Approval by:	Standards and Guidelines Committee Trust Policy Committee Executive Team Meeting		**Approval date:**	10/05/2019
Operational Date:	May 2019		**Next Review:**	May 2024
Version No.	2	**Supercedes**	Version 1	
Key words:	Choking, Asphyxiation, Aspiration, Dysphagia or Eating, drinking or swallowing difficulties (EDS)			
Links to other policies	• First Aid at Work. • Medicines Code. • Royal Marsden Manual of Clinical Procedures and Policies (access available from the HUB). • Food, Fluid and Nutrition Policy. • Food Hygiene for Non-Catering Staff Policy. • Prioritising the Mealtime Experience Policy. • Adverse Incident Reporting and Management Policy • The Reporting of Injuries, Diseases and Dangerous Occurrences Regulations (NI) 1997 (RIDDOR) Procedural Arrangements.			

Date	Version	Author	Comments
19/03/2015	0.1	Karen Cunningham K Devenney A Crocker	
20/11/2015	0.3	K Cunningham K Devenney C Donnelly A Crocker	Amendments following Sub Group Meeting
15/01/2016	0.4	K Cunningham	Amendments following Group Meeting
16/03/2016	0.5	K Cunningham A Crocker	Further Group amendments
06/04/2016	0.6	K Cunningham A Crocker	Further Group Amendments

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		C Donnelly	
21/04/2016	0.7	Patient Choking Group	Final Amendments prior to Trust wide consultation
28/07/2016	0.8	K Cunningham A Crocker C Donnelly	Sub Group Final amendments
24/11/2016	0.9	K Cunningham A Crocker Catherine Donnelly	Amendments before presentation to Standards & Guidelines Committee
03/04/2019	1.1	Ana Marie Magorrian A Crocker	Amendments made following UK and BHSCT implementation of International Dysphagia Diet Standardisation Initiative IDDSI

1.0 INTRODUCTION / PURPOSE OF POLICY

1.1 Background

In May 2014 the Health & Safety Executive (HSENI) advised that if a death or major injury arises due to service user choking (see definition 4.1), in connection with the Trust's work activities, and it could have been prevented by the Trust through risk assessment, identifying and implementing control measures or failure to do any of these, this should be reported under RIDDOR (Reporting of Injuries, diseases and Dangerous Occurrences Regulations (NI) 1997).

Evidence shows that specific groups of individuals who have eating, drinking and swallowing (EDS) difficulties, known as dysphagia, have a higher risk of choking.

The Trust is committed to the prevention and management of choking with the full knowledge that choking is complicated, and while some risks can be identified and managed, other risks are complex to manage, and will require collaborative working from specialist areas. Anyone could choke at any time. There will be choking events that cannot be predicted. These low probability high impact choking events have no identifiable risks. Whilst it is not possible to prevent all episodes of choking, working together to reduce the risk of choking and improve the safety of individuals who have EDS is essential.

1.2 Purpose

The purpose of this policy is to develop a resilient system that supports early identification of children and adults who may have an increased risk of choking, and develop supports to help manage and reduce that risk.

1.3 Objectives

1. They must ask people if they have any swallowing or choking needs, and find out how to meet their needs. Recognise when a person is at risk and take steps to assess and reduce the risk, this may include appropriate onward referral.

2 To ensure that the needs of patients, clients and service users with any swallowing or choking difficulties are appropriately assessed, steps are taken to reduce risks and relevant onward referral is completed.

3 To share information about people's swallowing and choking needs with other healthcare providers, when they have consent or permission to do so.

4 To ensure that patients, clients and service users receive food and drink which they can safely manage, and to provide the appropriate support they need to eat and drink.

5 To ensure that adequate documentation, using the examples provided in this Policy, are retained for patients, clients and service users with swallowing or choking difficulties.

6 Ensure all staff supporting people with swallowing or choking needs has access to appropriate training this may include eating, drinking and swallowing awareness training, choking awareness and first aid response.

2.0 SCOPE OF THE POLICY

This is a Trust-wide policy applicable to all staff who care for adults and children with eating, drinking and swallowing difficulties and or identified choking risks. It relates to all patients, clients and service users in all Trust Services including Day Care, Residential, Acute in-patient, client/service users and Domiciliary Care, nurseries, schools and home.
An easy read guide to this policy has been developed **(Appendix 17).**

3.0 ROLES/RESPONSIBILITIES

Ward, Department & Facility Managers should:

1. To ensure that food provided to patients, clients and service users on a modified dysphagia diet is of the correct consistency, is prepared as recommended and has not altered following preparation.
2. To ensure patients, clients and service users with a choking risk are clearly identified.
3. Consider referral to SLT for a swallowing assessment using indicators **(Appendix 5)** for all patients, clients and service users who show the symptoms of eating, drinking and swallowing difficulties (EDS) (dysphagia) or choking risk.
4. To ensure that staff have the necessary knowledge to assess the choking risk, make recommendations and take appropriate action to manage and reduce this risk wherever possible. Available Training Programmes (**Appendix 8**).
5. To ensure adequate storage arrangements to prevent accidental ingestion of prohibited food items including thickening agents. (Refer to Section 7 References).
6. To ensure that the general advice to help someone take medications when they have a choking risk is communicated to and implemented by all staff **(Appendix 15 & 10).**
7. To refer patients, clients and service users to the appropriate member of the multidisciplinary team for assessment and recommendations when any of the following impact on their risk of choking:
   a) difficulty taking medication or suspected side effects from medication
   b) breathing difficulties or recurrent chest infections
   c) difficulty maintaining a stable upright position while eating and drinking
   d) difficulty independently feeding
   e) oesophageal symptoms for example increased reflux

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f) dental pain, dental related oral swelling, loss of or ill- fitting dentures, damage to the dentition (teeth).

8. To implement the 'Prioritising of Mealtime Experience Policy'.
9. Where MUST scores are completed, to ensure that a Malnutrition Universal Screen Tool (MUST) has been completed accurately. MUST will identify patients at risk of malnutrition. Malnutrition may have a negative impact on an individual's ability to swallow. All patients with a newly diagnosed dysphagia should be referred to dietetics **following** assessment by SLT. Patients with a deteriorating swallow which is likely to significantly impact on nutritional intake should be referred to dietetics **following** assessment by SLT. Advice should be sought from a Dietitian, through local referral arrangements, where there are nutritional or hydration concerns following commencement on a texture modified dysphagia diet. (**Appendix 9).**

Patients should be referred to the Dietetic Service in the following circumstances:

- with an accurate MUST score of 2 or above, this score identifies patients at risk of malnutrition. Malnutrition may have a negative impact on an individual's ability to swallow or a deteriorating swallow may cause a patient to develop malnutrition.
- when commenced on a texture B or C diet following assessment by a SALT
- with a MUST score of 2 and above and commenced on a texture D or E diet following assessment by a SALT.
- who are consuming teaspoons amounts of food or nothing orally for a period of 5 consecutive days following SALT assessment.

10. To ensure that discharge planning includes a prescription request for thickener forwarded to the GP and to provide an interim supply as per local arrangements.
11. To educate and support patients, clients and service users on how to avoid and/or modify high risk choking foods, adopt safe eating behaviours and foster safe eating environments to help reduce their risk of choking **(Appendix 15).**
12. To ensure staff have considered and recorded actions following choking events to help prevent further choking. **(Appendix 1).**
13. To ensure the correct reporting of all choking episodes where the patients, clients and service users suffers harm in accordance with the Adverse Incident Policy. Any incidence of sudden death, including death by choking must be reported to the PSNI and to the Safeguarding Unit and RQIA.
14. To ensure that all alerts, newsletters and safety briefs are brought to the attention of all staff.
15. To ensure choking risks are reflected on Service Area/Directorate Risk Registers.
16. To ensure staffing levels and skill mix are adequate to support patients, clients and service users eating and drinking **(Appendix 4 & 8)**.
17. To complete a Choking / Dysphagia risk assessment for patients, clients and service users with identified choking risks. (Sample risk assessment **Appendix 2 a, b & c)**.
18. Ensure patients receive a prescription from their GP when thickener for home use is required.
19. To ensure that staff working with high risk patients, clients or service users are aware of their roles and responsibilities in managing the associated risks and have access to adequate training.
20. To provide support or alternative formats in terms of communication support or linguistic needs, if required, to communicate the policy.

Staff involved in patients, clients and service users care should:

1. Be involved in the care planning process for people at risk of choking.
2. Be aware of the consequences of not following an agreed eating, drinking and swallowing care plan. Staff should report, in discussion with their managers, all incidents where eating, drinking and swallowing care plans were not followed

placing the person at risk, e.g. person given wrong food/drink, this would include near misses. Staff should follow incident reporting policy.

3. Consider referral to SLT for a swallowing assessment using indicators **(Appendix 5)** any time eating, drinking and swallowing (EDS) concerns are raised or a new risk of choking is suspected on oral intake.
4. Support the patients, clients and service users to make a risk based decision regarding their choice of food where possible. **Refer to page 12 for further information on Risk Feeding.**
5. Have adequate training to be able to recognise and know how to prepare/present food and fluids to the patients, clients and service users according to their eating and drinking recommendations. **(Appendix 8).**
6. Show awareness of the risk of choking and the steps that can be taken to reduce risk.
7. Ensure knowledge and competence in the first aid response for choking including those patients, clients and service users who are wheelchair users. **(Appendix 15).**
8. Be aware of when and how to report choking. Report all choking events that require intervention that could have resulted in harm. An example of a record of all actions to consider following a choking incident can be found in **Appendix 1.** This form can be used to evidence what actions have been considered to help reduce the risk of further choking and to support risk management plans. A copy should be retained in the patients, clients and service users notes.
9. Be aware of how to access resources and specialist healthcare professionals that can help reduce risk of choking in relation to dysphagia, unsafe eating behaviours, positioning, respiratory or chest care, medication prescribers, advocacy. GI/reflux management and oral health. This may include SLT, OT, Physiotherapy, Pharmacy, Medical and Dental staff.
10. Be aware of the International Dysphagia Diet Standardisation Initiative (IDDSI) Further information on IDDSI can be found at http://iddsi.org/ dysphagia diet advice leaflets based on this guidance **(Appendix 3).**
11. Ensure capacity and consent has been considered, (DHSS Consent for Examination Treatment or Care) If a person with identified choking risk is assessed as not having capacity and is restricted from accessing food/areas, e.g. locked kitchens or kitchen cupboards ensure consideration has been given to the Mental Health (Northern Ireland) Order 1986.
    Guidance on the principles to be applied by those involved in taking decisions about an individual's care and treatment that might result in the deprivation of that individual's liberty can be accessed and restrictive interventions for Adult and Children's Services
12. Ensure all decision making is guided by and takes account of individual rights as enshrined in the Human Rights Act 1998 in particular Article 5 (1), 5 (4), Article 8and Article 14.
13. If patients, clients or service users, as a result of their behaviours and the consequent risk of choking, are prevented from accessing high risk foods, consideration should be given to the Mental Capacity Act Deprivation of Liberty Safeguards.
14. To participate in Choking / Dysphagia risk assessment for patients, clients and service users with identified choking risks when indicated. (Sample risk assessment Appendix **2** a, b & c).

The Speech & Language Therapy Department should:

1. Consider referrals, undertake assessments and produce care plans for people at risk of choking due to oral-pharyngeal dysphagia.

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2. To communicate the risks of choking to patients, clients and service users with identified eating, drinking and swallowing (EDS) difficulties (dysphagia) and their staff and carers.
3. Work with the multidisciplinary team to optimise safety, nutrition and hydration. Make onward referrals to MDT as necessary i.e. Dietetics.
4. Provide Eating, Drinking and Swallowing awareness training to staff and patients, clients and service users.
5. Contribute to capacity assessments in relation to the risk of choking **(**Example **- Appendix 10).**
6. Should report if they observe incidents where eating, drinking and swallowing care plans were not followed placing the person at risk, e.g. person given wrong food/drink, this would include near misses. Staff should follow incident reporting policy.
7. To contribute to identifying when a Choking / Dysphagia risk assessment is required and participate when appropriate. (Sample risk assessment Appendix **2** a, b & c).

The Catering Department should:

1. Provide food for people on dysphagia modified diets in line with International Dysphagia Diet Standardisation Initiative (IDDSI).
2. Ensure that as far as possible a choice of modified meal and snacks of the appropriate texture are available. Where modifications cannot be achieved by Catering, further modification may be required prior to serving at Ward level. Food should be checked by staff before serving.
3. To communicate regularly with services in relation to specific requirements.
4. To work in conjunction with SLT and Dietetics, using International Dysphagia Diet Standardisation Initiative (IDDSI) to ensure foods of the correct consistency which meet the needs of patients with eating, drinking or swallowing (EDS) difficulties (dysphagia) are provided.
5. To access training for staff to ensure the risks of providing inappropriate consistencies are clear.

The Pharmacy Department should:

1. Increase awareness and highlight consequences of oral formulation tampering. Choosing Medicines for Patients unable to take solid oral dose forms
2. Provide advice and medication review where requested.

The Dietetics Department should:

1. To provide advice to patient, client or service users referred to the service who have been placed on modified diets.
2. Assess the adequacy of texture modified diets in relation to patient's nutritional requirements.
3. Provide advice with regard to manipulating food and fluids to optimise nutritional value and meet nutritional requirements. This will include the provision of supporting literature.
4. Select the correct texture of oral nutritional supplements (ONS) if required following advice provided by SLT.
5. Discuss the need for enteral or parenteral nutrition with the medical team where the patient is unable to meet their nutritional requirements orally.
6. Ensure the patient receives a prescription from their GP when pre-thickened ONS are required for home use.
7. Ensure follow up is arranged as required.

8. Work with catering colleagues to code menus accurately thus ensuring safe choices can be made.
9. Assist staff tasked with helping patients make appropriate food choices by providing a manual which will be available at ward level and electronically.

Social Workers and Care Managers should:

1. Ensure capacity and consent has been considered.
   If a person with identified choking risk is assessed as not having capacity and is restricted from accessing food/areas, e.g. locked kitchens or kitchen cupboards ensure consideration has been given to the Mental Health (Northern Ireland) Order 1986.
   Guidance on the principles to be applied by those involved in taking decisions about an individual's care and treatment that might result in the deprivation of that individual's liberty can be accessed and restrictive practices interventions for Adult and Children's Services
2. Ensure all decision making is guided by and takes account of individual rights as enshrined in the Human Rights Act 1998 in particular Article 5 (1), 5 (4), Article 8and Article 14.
3. Ensure that the placement or service meets the assessed needs of the person with a choking risk. e.g. staff have adequate training, see matrix **(Appendix 8**). As part of their annual review of placements, must check that individuals are receiving annual dental and health checks.
4. Quality assure that private services have reported all choking incidents and provided copies of incident forms to the trust quality support team.
5. To check if eating, drinking and swallowing care plans are being followed and all non-compliance issues reported during review meetings. Social Work should seek out the Care Plans relating to eating and drinking from SLT and Dietetics as part of the Care Management process. Communication should be timely to ensure that care plans are shared with relevant parties e.g. Care Providers, Nursing Homes and Day Centres.

The Health & Safety Department should:

- The Health & Safety Managers will use the following criteria to assist in judging if an incident is reportable or not under RIDDOR, upon receipt of a Trust incident report form and through Datixweb:
- To organise an external provider for the provision of first aid training for staff throughout the Trust in accordance with the First Aid at Work Regulations (NI) 1981 and associated Approved Code of Practice (refer to the Trust's First Aid at Work Policy for further information).

Examples of RIDDOR reportable service user choking events include

A Service User chokes and dies. This service user has choked previously and is felt to be at risk of choking, but there is no evidence of any assessment or action to reduce the risk.

A Service User chokes on a high risk choking food. They have *been assessed as being at risk of choking and have a care plan stating that they require* supervision when eating *and should be protected from and not have access to certain high risk choking foods.*

An incident may not be reportable if:

a) The service user, whilst vulnerable, was not specifically at risk of choking and was able to make risk-based decisions in relation to what they ate; or
b) The service user choked on something that they were allowed to access to (according to the risk assessment) or
c) The supervision and storage of restricted items was adequate.

The Health Improvement Department should:

Raise awareness of choking risk and importance of health promotion in related areas including good oral care, respiratory care, posture and seating.

The Dental Department should:

Dental Services provide assessment or treatment for inpatients only, as per protocol. All other persons with an identified choking risk should be referred to their usual dental service provider e.g. General Dental Practitioner or Community Dental Services.

The Occupational Therapy Department should:

Provide a seating assessment, independent feeding assessment and other specialised assessments, such as sensory assessment, where available.

The Physiotherapy Department should:

Provide chest assessment and chest physio for people with breathing difficulties and regular chest infections that are contributing to their choking risk.
To undertake physio assessment, post choking incident, if there are concerns regarding aspiration.

4.0 KEY POLICY PRINCIPLES

4.1 Definitions

Asphyxiation. Choking can lead to asphyxiation when the airway is blocked or closed and air cannot enter the lungs cutting off oxygen to the brain. This can result in a loss of consciousness and can, at times, be fatal.

Aspiration
Where food or drink enters the airway and can result in a choke, asphyxiation and chest infections or pneumonia. Aspiration may be *oropharyngeal* with food or drink entering airway direct from the mouth or *gastroesophageal* as a result of material overspilling or refluxing back from the oesophagus or stomach. Aspiration often results in coughing, spluttering and distress but it can also be silent with no outward signs.

Choking is “an acute episode in which the patient coughed incessantly or experienced a colour change (with inability to speak or cough effectively) while ingesting food or drink. The solid or liquid usually has to be expelled to terminate the event“ Fioritti et al 1997.

Dysphagia or Eating, drinking or swallowing difficulties (EDS) is defined as “*difficulty in oral preparation for the swallow or in moving a bolus from the mouth to the stomach*” (RCSLT 1998). Dysphagia is a difficulty swallowing. It is caused by a

breakdown in the pharyngeal and/or oesophageal swallowing process due to structural or neuromuscular impairments. Dysphagia can be exacerbated by developmental or behavioural issues which can be common among children and adults with a learning disability or older people with dementia. Dysphagia can lead to food or drink entering the lungs instead of the stomach, this is known as aspiration.

It is recognised that whilst anyone can experience a choking episode there are a number of client groups for whom the risks are magnified, in particular people who have **dysphagia**

Thickener is a powder added to a liquid or food to make the consistency thicker. Thickeners can be prescribed as a treatment for people who can no longer swallow normal liquids safely.

4.2 Policy Principles

1. Awareness

The Trust will raise awareness of choking risks and the steps that can be taken to reduce the risks. Highlight importance of following care plans for children and adults identified as having an eating, drinking or swallowing difficulty (dysphagia) or choking risk.

Raising awareness includes:

- Recognition of signs and symptoms that may indicate a risk of choking
- Emergency aid response to choking
- Referral processes to SLT or multiagency team
- Food preparation
- Skills to support individuals at risk of choking with their eating and drinking
- Care planning and support to meet individual needs.
- Sample risk assessment proformas

2. Identification and Screening

To ensure that patients, clients and service users at potential high risk of choking are risk assessed, risks documented and appropriate risk management implemented including referral where appropriate.

Ensure all initial admission service documentation has clear questions to identify people with Eating, Drinking and Swallowing (EDS) difficulties or a known risk of choking, e.g. NISAT, NAPOC, About You. These questions should be asked when a person is new to a relevant Service Facility, when there is a change to health which may impact on EDS and also on all reviews.

Services make sure that if someone has a known choking risk or EDS difficulties, this is clear on their notes or records. A clear system to highlight or flag up someone with a choking risk or EDS difficulty, so that all staff are aware and can access a care plan at mealtimes.

Ensure early detection of people who have no known EDS difficulties or choking risk, but are presenting with new difficulties. **(Appendix 9).**

Ensure that all staff can recognise people who may have EDS difficulties or be at risk or choking and know how to escalate concern.

Ensure monitoring of people where choking risks may change due to deteriorating health indicators (**Appendix 5**).

Ensure robust systems are in place for timely sharing of information with other services, e.g. food providers. Systems in place to ensure information is highlighted or flagged up for any individual with a known choking risk or EDS difficulty, that is transferred or discharged from a service e.g. an alert is available on Paris to highlight swallowing difficulties.

3. Risk Assessment

The consent of the person must be obtained wherever possible, before any medical investigation or assessment is undertaken. It is essential that all decisions are clearly documented. When the person is unable to give informed consent follow best interest decision guidelines. The Trust will provide guidance to Ward, Department and Facility Managers, Ward Sisters / Charge Nurses, on risk assessment processes to assess a person's risk of choking and strategies to minimise these risks within their areas of responsibility. Staff should use the Trust standard risk form, a locally agreed risk form or the adapted NPSA risk form in **Appendix 2 a**. SLT assessment and care plan may be also be part of the risk assessment action plan. A risk assessment should be completed for all patients who have a risk of a choking episode. The NPSA is a more comprehensive assessment for use in complex management.

Appendix 9 highlights an example of good practice when someone is highlighted as having a choking risk. (An example of a completed Choking Risk Assessment form adapted from the NPSA is available at **Appendix 2 b**).

4. Reporting and Learning

The Trust will promote the investigation and shared learning from patients, clients and service users choking incidents to prevent further similar occurrences**. (Appendix 1).**

5. Safeguarding.

Ensure staff show knowledge of consent and capacity legislation and best interest processes. Establish the capacity of a patient, client or service user to be able to make a risk based decision regarding their choice of food. Where the person does not have capacity to support them to make as many decisions for themselves or to make best interest decisions in the interest of their health and safety. **(Appendix 10).**

If a person does have capacity and continues to eat preferred food and drink against advice on swallow safety, the risk feeding decision should result in a plan which balances safety and quality of life as equally as possible, taking fully into account the personal, cultural and religious beliefs of the individual. This should be documented in the patients' notes.

Ensure effective commissioning and monitoring of placements for people who have Eating, Drinking and Swallowing (EDS) difficulties or are at risk of choking.

If a parent or carer is in dispute about the choking/ dysphagia management plan and the service user is deemed to be at significant risk variance, should be fully documented and referred to the consultant and/or GP for further team discussion regarding need for safe guarding advice or referral.

In some cases, as a result of best interest discussions, a decision may be taken to limit a person's access to particular environments, within for example a residential setting in order to minimise choking risk and keep that person safe. This decision will be backed up by appropriate risk assessments. It should be recognised that if this action is taken, it may result in a deprivation of liberty which would fall under the Deprivation of Liberty Safeguards.

In such cases an exceptional care plan may be agreed by the Multi Disciplinary Team (MDT) e.g. risk feeding.

Risk Feeding

When a person continues to eat and drink despite a risk of aspiration and or choking, this is referred to as risk feeding. Risk feeding may be put in place for one or more of the following reasons:

- Advance stages of illness
- The person's swallow is not safe and is unlikely to improve
- When preferred food and drink takes priority over swallow safety
- Tube feeding options are declined or inappropriate

The risk feeding decision should result in a plan which balances safety and quality of life as equally as possible, taking fully into account the personal, cultural and religious beliefs of the individual. This should be documented in the patients' notes.

6. Prevention

The Trust will encourage the development of safe systems of work, local protocols and procedures in relation to the prevention of choking and ensure patients, clients and service users are given safe and appropriate food and drink, MDT and SLT Care Plans are followed, advice on good oral care, respiratory care, posture and seating, reflux management and medication reviews.

The Trust will help empower service users and their carers to manage risk by increasing their knowledge of high risk foods, the importance of encouraging safe eating behaviours and promoting safe eating environments.

7. Information & Training

The Trust will ensure that staff are adequately trained to support patients, clients and service users with eating, drinking and swallowing (EDS) difficulties and those at high risk of choking.

The Trust will ensure the availability, in Trust facilities, of modified foods at all mealtimes/snacktimes for patients, clients and service users.

The Trust will ensure staff have an awareness of available resources and sources of expert advice.

Service Areas should agree a consistent alert system to identify patients, clients and service users at high risk of choking e.g. use of alert system on Paris.

Another example of good practice is the bed side care plan (Acute Setting) **(Appendix 11)** or the Personal Place Mat (Community Setting). Learn more about Personalised Placemats and download of a Placemat Template, with instructions. (Appendix 12)

Ensure clear communication when going into hospital. An example of good practice would be promotion of Hospital Passports **(Appendix 12)**.

To adequately train staff, who support patients, clients, and service users with swallowing difficulties or at risk of choking, in eating, drinking and swallowing awareness training and to make a first aid response if a person does choke. Staff can self-assess their awareness, knowledge, skills and confidence by using the example tool at **Appendix 14.**

- Access Eating, Drinking and Swallowing awareness eLearning and the choking awareness DVD from the hub eLearning site

- The Resuscitation Council have very clear guidelines on the treatment of choking which can be accessed by clicking on the link above

- The Trust's Resuscitation Officers provide the following programmes:

  - In-hospital Life Support (Hospital Staff) – 3 hrs (Adult) 3 Hrs (Paediatrics)

  - Community Basic Life Support (Community Staff) – 2 hrs or 3 hrs (with AED)

  - Please refer the Trust's Statutory/Mandatory Matrix for further details.

- The Resuscitation Officer should be contacted in relation to arranging specialised training sessions for particular Service Areas/Patients/Service Users, incorporating Ward based scenarios. (Refer to **Appendix 8** - Available Training Programmes).

5.0 IMPLEMENTATION OF POLICY

5.1 Dissemination

This Policy is required to be implemented by all Directorates.
All Staff, Managers and Departments with specific responsibilities are required to comply with this Policy as detailed.
If support or alternative formats are required in terms of communication in relation to the policy, this will be provided.
An Easy Read Guide has been developed in relation to this policy **(Appendix 17)**.

5.2 Resources

Choking awareness resources have been developed as part of a Personal and Public Involvement PPI project to help raise awareness of choking within adult learning disability services http://helpstopchoking.hscni.net/. A choking awareness DVD (22 minutes) is available to all staff on eLearning. You can access Eating, Drinking and Swallowing eLearning from the Hub eLearning site.

Please refer to Section 7 – Evidence Base References and Appendices 1 – 17 for further Resources.

5.3 Exceptions

There are no exceptions.

6.0 MONITORING

This policy provides guidance to support managers to implement and observe the cumulative impact of work to address, awareness, screening and identification, risk assessment, reporting and Learning, safeguarding, training, prevention and resources in their area. It is proposed that this work would be monitored to explore what works best to help reduce death and harm from choking in different services. It is proposed that learning from the implementation of this policy will be reviewed and the policy will be updated to highlight good practice and what different services require.

This policy will be monitored by Service Areas reviewing the incidence of choking incidents and their management of such.

7.0 EVIDENCE BASE / REFERENCES

Information Available from the Belfast Trust

- Information book to help raise awareness of choking, available from the Belfast Health & Social Care Trust Hub.

- Belfast Health & Social Care Trust choking awareness DVD (available from eLearning).

- Activities and resources are also available from the Belfast Health & Social Care Trust Awareness website - help stop choking desktop application and ios app available from: helpstopchoking.hscni.net (list of resources in **Appendix 15**).

- NI Heroes of Youth Awards

Journal References

- Guthrie, S et al (2012). Capacity to choose and refuse? A case study. ADVANCES IN MENTAL HEALTH AND INTELLECTUAL DISABILITIES, Vol. 6 No. 6, pp. 293-300,.

- Cash, S., & Shinnick, A. (October 2008). Basic life support and children with profound and multiple learning disabilities. paediatric nursing, Vol 20 No 8, pp. 38 - 39.

- Howseman, T. (November 1, 2013). Dysphagia in people with learning disabilities. Learning Disability Practice , Vol 16, No 9, pp. 14 - 22.

- Partnership, H. S.-a. (2012). Reducing the risk of choking for people with a learning disability A Multi-agency review in Hampshire.

Other External References

- Patient, client, service user Safety Alert – HSC (SQSD) 6/15 – 24/2/15 – Risk of death from asphyxiation by accidental ingestion of fluid/food thickening powder.

- International Dysphagia Diet Standardisation Initiative (IDDSI) Further information on IDDSI can be found at http://iddsi.org/

- Reduce the risk of choking for people with a learning disability – A multi-agency review in Hampshire. Hampshire Safe Guarding Adults Board Multi-Agency Partnership.

- Choking Prevention Policy 2014, Surrey County Council.

- IHaL report of the reasonable adjustments in the management of dysphagia in people with learning disabilities, includes a summary of the research evidence and guidance as well as links to resources and examples from practice. Available from http://www.improvinghealthandlives.org.uk/publications

- NICE clinical guideline 76 Medicines adherence - Involving patient, client, service users in decisions about prescribed medicines and supporting adherence Issued: January 2009.

- Reducing the risk of choking for people with a Learning Disability; a multi-agency review, Hampshire Safeguarding Adults Board.

- Choosing Medicines for Patients unable to take solid oral dose forms

- Safety and Quality Reminder of Best Practice Guidance

- Management and advice for patients/clients with swallow/dysphagia problems SQR/SAI/2015/015(OPS/MH/LD/AS) HSC & PHA

- Referral protocol for inpatients requiring dental treatment or assessment at the School of Dentistry

- Resource Manual for Commissioning Services for SCLN: Dysphagia (2014) RCSLT.

- Resource Manual for Commissioning Services for SCLN: Head and Neck Cancer (“2014) RCSLT.

- Speech and Language Therapy Provision for People with Dementia – RCSLT Position Paper 2014.

8.0 CONSULTATION PROCESS

This policy has been devised in collaboration with the Trust’s Health & Safety Managers, Joint Health & Safety Committee, Co-Directors and Senior Managers throughout the Trust.
Consultation with staff and their trade union representatives during development and introduction of a policy is a legal requirement and it will also help to enhance employee relations, ref: Health & Safety (Consultation with Staff) Regulations (NI) 1996 and The Safety Representatives and Safety Committee Regulations (NI) 1979.
Service users were consulted on the Easy Read Guide (Appendix 17).

9.0 APPENDICES / ATTACHMENTS

Appendices 1 - 8 are Mandatory

Appendices 9 – 17 are examples of Good Practice.

Appendix 1 - Immediate Actions to Consider Following A Choking Event
Appendix 2 - 2a - MDT Risk Assessment Form
2b - Completed Example Choking / Dysphagia Risk Assessment
2c – Decision Tree
Appendix 3 - International Dysphagia Diet Standardisation Initiative (IDDSI) http://iddsi.org/
Appendix 4 - Supervision Levels
Appendix 5 - Indicators For Referral To Speech & Language Therapy For Eating, Drinking & Swallowing Assessment
Appendix 6 - SLT Adult Swallowing Care Plan
Appendix 7 - Choosing Medicines for Patients Unable to Take Solid Oral Dose Forms
Appendix 8 - Available Training Programmes

Appendix 9 - Example Of Good Practice When Someone Is Highlighted As Having A Choking Risk
Appendix 10 - Choking Capacity Questions
Appendix 11 - Bedside Care Plan
Appendix 12 - Personal Place Mat Template
Appendix 13 - Hospital Passport
Appendix 14 - Choking Awareness Self-Assessment
Appendix 15 - Choking Awareness Resources from Help Stop Choking Project.
Appendix 16 - Flowchart for Reporting Choking Events
Appendix 17 – Easy Read Guide to this Policy.

10.0 EQUALITY STATEMENT

In line with duties under the equality legislation (Section 75 of the Northern Ireland Act 1998), Targeting Social Need Initiative, Disability discrimination and the Human Rights Act 1998, an initial screening exercise to ascertain if this policy should be subject to a full impact assessment has been carried out.

The outcome of the Equality screening for this policy is:

Major impact ☐
Minor impact ☐
No impact. X

11.0 DATA PROTECTION IMPACT ASSESSMENT

New activities that involve collecting and using personal data can result in privacy risks. In line with requirements of the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 the Trust has to consider the impacts on the privacy of individuals and ways to mitigate against the risks. Where relevant an initial screening exercise should be carried out to ascertain if this policy should be

subject to a full impact assessment (see Appendix 7). The guidance for conducting
Data Protection Impact Assessments (DPIA) can be found via this **link.**
The outcome of the DPIA screening for this policy is:

Not necessary – no personal data involved X ☐

A full data protection impact assessment is required ☐

A full data protection impact assessment is not required ☐

If a full impact assessment is required the author (Project Manager or lead person) should go ahead and begin the process. Colleagues in the Information Governance Team will provide assistance where necessary.

12.0 RURAL IMPACT ASSESSMENTS

From June 2018 the Trust has a legal responsibility to have due regard to rural needs when developing, adopting, implementing or revising policies, strategies and plans, and when designing and delivering public services.
It is your responsibility as policy or service lead to consider the impact of your proposal on people in rural areas – you will need to refer to the shortened rural needs assessment template and summary guidance on the Belfast Trust Intranet. Each Directorate/Division has a Rural Needs Champion who can provide support/assistance in this regard if necessary.

13.0 REASONABLE ADJUSTMENTS ASSESSMENT

Under the Disability Discrimination Act 1995 (as amended), the Trust has a duty to make reasonable adjustments to ensure any barriers disabled people face in gaining and remaining in employment and in accessing and using goods and services are removed or reduced. It is therefore recommended the policy explicitly references "reasonable adjustments will be considered for people who are disabled - whether as service users, visitors or employees.

SIGNATORIES

(Policy – Guidance should be signed off by the author of the policy and the identified responsible director).

_____ **Date:** _____
Author

_____ **Date:** _____
Director

Appendix 1 - Actions to Consider Following a Choking incident

This form should be completed by person(s) responsible for providing direct care. Ensure you consult with the service user and gain their consent and involvement in identifying risks, also carers/ families who know the person best. It will provide a record of all actions considered following a choking incident to help prevent further choking. This information can contribute to a choking risk management plan, if needed.

Please note all incidents, near misses and errors should be reported through the DATIX incident reporting system.

Name of patient/client	**Date of choking event**
Date form completed	**Name of person completing form** **List all persons who contributed**
Describe what the person was eating, the way they were eating, the environment at the time of the choke and if they cleared any blockage?	**Describe level of intervention required** Reassurance/prompt to cough/backslap/abdominal thrust/paramedic/lost consciousness/ A&E/admission. **Medical exam following incident? y/n**

Questions to ask following a choking incident	**No**	**Yes**	**If Yes, Actions to consider**	**Completed by and date**	**Comments if no action give reason.**
1. Is there suspected aspiration of material into the lungs or a change in the person's breathing effort, rate or sounds?			Medical review Chest Physiotherapy		
2. Does any chronic respiratory condition appear worse?			GP/ Medical or Physiotherapy opinion as appropriate		
3. Is this a **new** difficulty? i.e. the person has no known choking/ Eating drinking or swallowing (**EDS**) difficulties?			Consider referral to SLT if meets referral criteria.		
4. Recent deterioration in observations of general health?			Medical review		
5. Does the person have worsening swallowing skills due to ill health?			Medical review Referral to SLT if meets referral criteria		
6. Is the person **unable** to maintain an awake alert state for duration of feed/ meal?			Ensure awake and alert before all mealtimes. Medical review.		
7. Is there concern that the EDS care plan was not applied? E.g. person choked on food that is **not** recommended?			Carers aware of EDS Care plan. Personal Place Mat in place Review access to high risk foods		
8. Did person choke on food that **is** recommended on current diet?			Avoid high risk foods Refer to SLT		

Appendix 1 Continued…

	No	**Yes**			
9. Is there concern that the food preparation was inadequate? E.g. unsafe temperature, hard skin formed, texture/size?			Undertake safety checks with kitchen, food provider, and person preparing food.		

10. Does the person show unsafe eating behaviours? E.g. overfilling, fast pace, inadequate chewing, talking or moving.			Education on safe eating strategies. Consider behaviour Management plan.		
11. Is the person's ability to independently feed reduced?			Identify Support required, safe feeding guidance, PPM, bed side care plan, independent feeding assessment OT.		
12. Is the person's ability to maintain a stable and upright position throughout mealtimes reduced?			Temporary support to maintain upright stable position refer to OT for seating assessment		
13. Was specified specialist equipment **not** used?			Person had access to correct specialised equipment, e.g. dysphagia cup, non-slip mat, correct furniture?		
14. Do any oesophageal symptoms appear worse? E.g. reflux, vomiting.			Medical review		
15. Are there any oral health issues e.g. pain, dry mouth, thrush, loose teeth, caries, poor fitting dentures.			increase mouth care medical/ dental review as per protocol		
16. Does the person have difficulty swallowing medications?			Liaise with pharmacy/ medical team for medication preparation review		
17. Is there concern that medication is having negative side effects (e.g. drowsy, dry mouth)?			Liaise with pharmacy/medical team re medication review.		
18. Is there concern that first aid was **not** administered correctly?			Revise knowledge/skills Update training Practice drills		
19. Was the mealtime environment interrupted/rushed/noisy?			Protected mealtimes		
20. Is there a concern over the staff's level of experience or training?			Identify level of experience required check training		
21. Are there any staffing concerns impacting supervision?			Increase monitoring, specify supervision level Escalate to manager		

A risk assessment should be completed for all patients who have a risk of a choking episode.

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V2/July2016/SLT/AC

Appendix 2 a -

MDT RISK ASSESSMENT FORM

CHOKING/DYSPHAGIA RISK ASSESSMENT

DATE OF RISK ASSESSMENT/REVIEW MEETING……

Risk assessments carefully examine the person and their situation to identify factors that could cause or contribute to harm to the individual or to others. The assessment investigates whether adequate precautions are in place to prevent injury, ill health or other negative consequences, or if further measures are required.

This dysphagia risk assessment (based on the NPSA risk form 2006) seeks to answer the following questions:

- What is the current situation?
- What could go wrong?
- How serious is the harm to the person?
- How likely is the harm to occur?
- What actions are needed to prevent harm?
- How and when will the situation be reviewed?

People involved in the Risk Assessment

Name and contact details	**Indicate type of involvement, e.g. present for meeting, consulted**	**Signature** To indicate awareness and agreement
Person with Dysphagia		
Family member/Caregiver		
Advocate		
Residential Staff		
Respite Service		
Day centre staff		
School Staff		
SLT		
Dietician		
Community nurse or School Nurse		
PT		
OT		
GP		
Other (give details)		
Notes:		

NATURE OF PROBLEM

(e.g. describe type and severity of dysphagia (refer to risk of aspiration, choking, chest infection, nutritional comprise, dehydration and other)

☐ Is this a new problem
☐ or an existing problem that has worsened

OTHER EXISTING PHYSICAL HEALTH CARE NEEDS
(Include details of current medication)

CURRENT EATING AND DRINKING SITUATION
(Where meals are taken/level of support needed etc.)

PREVIOUS HEALTH/RISK ISSUES
(Include any previous factors which could potentially affect the swallow, rapid decline in swallow safety when unwell)

Appendix 2 a Continued…

ASSESSMENT OF LEVELS OF RISK

For further guidance see The NPSA *Guide to Levels of Risk of Negative Health Consequences* Dysphagia negative health consequences

Risk area	Level of Risk			Details
	Low Risk	Medium	High Risk	
INTRINSIC FACTORS				
Medical Diagnosis				
Cognitive function				
Level of alertness, Level of cooperation				
Fatigability / endurance				
Rapid decline due to ill health				
Postural control				
Oral Health				
Oral structures, motor function and sensation				
Pharyngeal structures, motor function, sensation				
Gastro-oesophageal reflux disease				
Underlying respiratory functions				
Seizure activity				
Behavioural difficulties				
Mental Health difficulties				
Medication				
Nutrition and hydration, weight				
Reliance on others for eating and drinking				

Risk area	Level of Risk			Details
	Low Risk	Medium	High Risk	
EXTRINSIC FACTORS				
Physical environment				
Social environment				
Access to eating and drinking equipment				
Staffing levels				
Patient's adherence				
Staff adherence				
Family adherence				

Appendix 2a Continued

DYSPHAGIA RISK MANAGEMENT PLAN

What Could Go Wrong (Risk Area)	Severity Of Problem			Likelihood Of Harm Occurring			What Needs To Be Done	Agreed Actions	Named Person Responsible For Actions	TIME-SCALE (date by which action is to be completed)
	High	Med	Low	High	Med	Low				
Name, role and Signature of people agreeing to this plan (please describe any disagreements)										

Appendix 2a Continued…

CONTINGENCY PLAN:

What action will be taken if situation deteriorates?

Who will be responsible for action?

Who will be informed?

What action will be taken in the event of an emergency?

Who will be responsible for action?

Who will be informed?

Date of next meeting/review:

Adapted from the NPSA risk form 2006 Dysphagia risk assessment form

Joe Bloggs dob 11/1/11
11 Somewhere Ave,
Someplace Town BTTT 111
Paris id 23445

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Appendix 2b

COMPLETED EXAMPLE CHOKING/DYSPHAGIA RISK ASSESSMENT

CHOKING/DYSPHAGIA RISK ASSESSMENT
DATE OF RISK ASSESSMENT/REVIEW MEETING……25/3/16

Risk assessments carefully examine the person and their situation to identify factors that could cause or contribute to harm to the individual or to others. The assessment investigates whether adequate precautions are in place to prevent injury, ill health or other negative consequences, or if further measures are required.

This dysphagia risk assessment (based on the NPSA risk form 2006) seeks to answer the following questions:

- What is the current situation?
- What could go wrong?
- How serious is the harm to the person?
- How likely is the harm to occur?
- What actions are needed to prevent harm?
- How and when will the situation be reviewed?

People involved in the Risk Assessment		
Name and contact details	**Indicate type of involvement, e.g. present for meeting, consulted**	**Signature** To indicate awareness and agreement
Person with Dysphagia	Person did not attend meeting but is felt to have capacity and risk management was discussed prior and after the meeting	
Family member/Caregiver Mrs Bloggs, Mother Tel 028900000	SLT discussed on the telephone prior to the meeting and after the meeting	
Advocate		
Residential Staff	Sandra Someone	
Respite Service		
Day centre staff	Tommy Somebody	
School Staff		
SLT	Amy Anyone	
Dietician		
Community nurse or School Nurse		
PT		
OT		
GP	Dr James Bond	
Other (give details)		
Notes:		

NATURE OF PROBLEM
(e.g. describe type and severity of dysphagia (refer to risk of aspiration, choking, chest infection, nutritional comprise, dehydration, other)

Joe is a 46 year old man with a medical history of learning disability, reflux and reduced mobility.
Joe has had 3 choking events which have required staff intervention including back slaps, abdominal thrusts and assessment at an emergency department. The reason for the choking is felt to be due to unsafe eating behaviours, eating at a fast pace, overfilling the mouth, eating food without a drink, swallowing without adequate chewing. Joe has had a swallowing assessment and does not have a dysphagia but has a continued risk of choking due to unsafe eating behaviours. There is no history of chest infections or concerns about weight or hydration.

Non-compliant with SLT recommendations. Joe agreed to trial a level 6 soft & bite sized dysphagia diet and have his food cut up to 1.5cm. Following the trial he choose to return to a normal diet and does not want to have his food cut up.

☐ ✓ Is this a new problem
☐ or an existing problem that has worsened

OTHER EXISTING PHYSICAL HEALTH CARE NEEDS
(Include details of current medication)

Joe is a 46 year old man with a medical history of learning disability, reflux and reduced mobility. Currently taking Omeprazole for gastroesophageal reflux disease (GERD)
Requires support with personal care.

CURRENT EATING AND DRINKING SITUATION
(Where meals are taken/level of support needed etc.)

Currently eats within dining room with general supervision, support to carry food and drink to table. Occasionally positions self out of view and eats unsupervised.

PREVIOUS HEALTH/RISK ISSUES
(Include any previous factors which could potentially affect the swallow, rapid decline in swallow safety when unwell)

No other known health risks

Appendix 2b Continued

ASSESSMENT OF LEVELS OF RISK

For further guidance see The NPSA *Guide to Levels of Risk of Negative Health Consequences* Dysphagia negative health consequences

Risk area	Level of Risk			Details
	Low Risk	Medium	High Risk	
INTRINSIC FACTORS				
Medical Diagnosis	✓			
Cognitive function	✓			
Level of alertness, Level of cooperation	✓			
Fatigability/ Endurance	✓			
Rapid decline due to ill health	✓			
Postural control	✓			
Oral Health	✓			
Oral structures, motor function and sensation	✓			
Pharyngeal structures, motor function, sensation	✓			
Gastro-oesophageal reflux disease		✓		Long term reflux
Underlying respiratory functions	✓			
Seizure activity	✓			
Behavioural difficulties	✓			
Mental Health difficulties	✓			
Medication	✓			
Nutrition and hydration, weight	✓			
Reliance on others for eating and drinking	✓			

Risk area	Level of Risk			Details
	Low Risk	Medium	High Risk	
EXTRINSIC FACTORS				
Physical environment		✓		Can at times position self out of site
Social environment		✓		Attention to task can be reduced if increased noise activity
Access to eating and drinking equipment	✓			
Staffing levels	✓			
Patient's adherence			✓	Refuses level 6 diet, does not want to have high risk foods modified or removed, e.g. food cut up
Staff adherence	✓			
Family adherence	✓			

Appendix 2b Continued

DYSPHAGIA RISK MANAGEMENT PLAN

What Could Go Wrong (Risk Area)	Severity Of Problem			Likelihood Of Harm Occurring			What Needs To Be Done	Agreed Actions	Named Person Responsible For Actions	TIME-SCALE (date by which action is to be completed)
	High	Med	Low	High	Med	Low				
Choke while eating		✓		✓			Ensure all staff are aware of choking risk, safe food choices and the safe eating strategies.	Create Personal Place Mat to remind staff of the choking risk.	Tommy Somebody	May 16
							Increase Joe's choking awareness, high risk foods and safe eating strategies.	Provide choking awareness sessions	Amy Anyone	May 16
							Ensure staff have update first aid training, swallowing awareness and choking awarness.	Check training record	Manager of day service	Annually May 16
							Ensure general supervision level, i.e. designated staff/carer remains within the immediate dining area observing at all times.	Ensure adequate staffing levels	Manager of day service	Continuous
							Agree safe mealtime management	All staff supporting mealtimes will Encourage a level 6 soft & bite sized dysphagia diet. Offer to cut up difficult foods.	Tommy somebody	May 16
Name, role and Signature of people agreeing to this plan (please describe any disagreements) Sandra someone, Tommy Somebody, DR James Bond, Amy Anyone										

Appendix 2b Continued

CONTINGENCY PLAN:

What action will be taken is situation deteriorates?
If there is a further choking event revise choking awareness and relook at risk management plan

Who will be responsible for action?
Tommy somebody

Who will be informed?
Amy Anyone Manager of day services and Dr James Bond

What action will be taken in the event of an emergency?
Remove food, choking first aid

Who will be responsible for action?

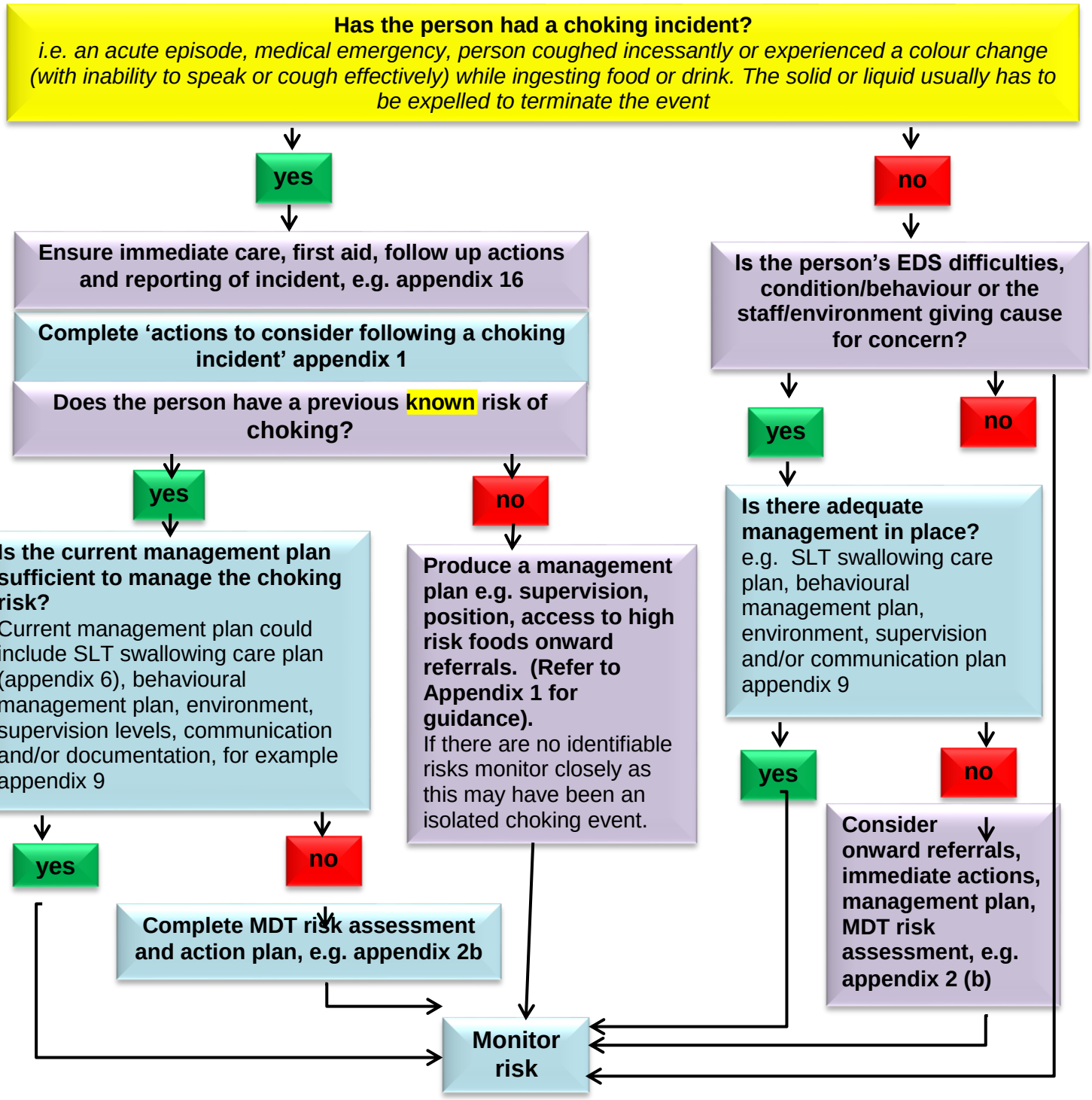
All

Who will be informed?
Follow choking policy guidance

Date of next meeting/review:

Appendix 2c - Decision Tree to help guide staff on when to complete a MDT choking risk assessment

Early identification and screening is essential to ensure that people at potential risk of choking are risk assessed, risks documented and appropriate risk management implemented including referral where appropriate. For some people increased supervision, a swallowing care plan or behavioural management plan may be sufficient to manage the risk. For a small number of people who have significant risk or are complex a highly individualised MDT choking risk assessment should be considered. This decision tree is to help guide staff on when to complete a MDT choking risk assessment (Appendix 2a).



Appendix 3 - International Dysphagia Diet Standardisation Initiative (IDDSI) advice leaflets further information on IDDSI can be found at http://iddsi.org/

- Level 0 thin paediatric
- Level 1 slightly thick paediatric
- Level 3 mildly thick paediatric
- Level 3 Liquidised - Paediatric
- Level 4 Extremely Thick - Paediatric
- Level 4 Pureed - Paediatric
- Level 4 Pureed - Foods to avoid - Paediatric
- Level 5 Minced and Moist - Paediatric
- Level 5 Minced and Moist - Food examples - Paediatric
- Level 5 Minced and Moist - Food to Avoid - Paediatric
- Level 6 Soft and Bite Sized - Paediatric
- Level 6 Soft and Bite Sized - Food examples - Paediatric
- Level 6 Soft and Bite Sized - Food to Avoid - Paediatric
- Level 7 Easy to Chew - Paediatric
- Level 7 Easy to chew page 2 of 2 paediatric
- Level 7 Easy to Chew - Food examples - Paediatric
- Level 7 Easy to Chew - Food to avoid - Paediatric
- Level 7 Regular - Paediatric
- Transitional Foods - Paediatric

- Level 0 Thin Adult
- Level 1 Slightly thick - Adult
- Level 2 Mildly Thick - Adult
- Level 3 Moderately thick - Adult
- Level 3 - Liquidised - adult
- Level 4 Extremely thick - adult
- Level 4 - Pureed – adult
- Level 4 - Pureed foods – Foods to avoid - Adult
- Level 5 – Minced & Moist - Adult
- Level 5 – Minced & Moist – food examples – Adult
- Level 5 – Minced & Moist – foods to Avoid - Adult
- Level 6 – soft & bite sized - Adult
- Level 6 – soft & bite sized – food examples – Adult
- Level 6 – soft & bite sized – foods to avoid - Adult
- Level 7 Easy to chew Adult page 1 of 2
- Level 7 Easy to Chew page 2 of 2 Adult
- Level 7 – easy to chew – food examples - Adult
- Level 7 – easy to chew – foods to avoid – Adult
- Level 7 – Regular – Adult
- Transitional Adult

Appendix 4 - Supervision Levels

The following supervision levels are guidance only and may be subject to change depending on changes in client's medical condition, behaviour, level of alertness, fatigue, familiarity with the environment and staff etc.

Levels of supervision are based solely on the SLT's opinion on the level of staff/carer supervision required to adhere to recommendations made by SLT following eating, drinking and swallowing assessment.

Levels of supervision around eating and drinking and swallowing only reflect the levels of supervision required to eat and drink FOOD ITEMS safely without causing the client to choke, aspirate, become malnourished or dehydrate and do not take into account other environmental or behavioural issues which may also cause safety issues around mealtimes.

There are three levels of supervision

Level 1 – General Supervision

Description:
Designated staff/carer remains within the immediate dining area while clients are eating and drinking, observing at all times. The staff member would be responsible for ensuring their familiarity with the SLT Eating, drinking and swallowing recommendations of clients as appropriate including provision of food and fluids according to the recommended textures.

Examples:
- Can eat/drink independently
- Risk of choking may be increased due to environmental factors/distractions

  - General monitoring for any signs of difficulty/aspiration and action to provide assistance if required.

Level 2-Direct supervision

Description:
Staff/carer supervises/assists a small number/group of clients while eating and drinking. This level of supervision may be used to provide verbal prompting regarding (staff need to be observing clients directly at all times)
- Rate of eating and drinking
- Volumes of food or fluid taken
- Use of correct utensils

Examples:
- Client may require verbal prompts/assistance
- To promote independence in eating/drinking
- To chew and swallow
- Reduce distractions in environment

  - Choking risk identified
  - Client needs to be monitored for signs of difficulty/aspiration

Appendix 4 Continued…..

Level 3-One-to-one supervision/support

Description:

Staff/carer provides full assistance/direct one- to- one support/supervision to an individual client while eating and drinking.
This will apply to people who require physical prompts/assistance, hand over hand feeding, support, monitoring and direction re eating and drinking recommendations at all times.

Examples: Client may require verbal and physical prompts/assistance due to

- Poor hand to mouth co-ordination
- Overloading spoon/cramming food
- Poor self-awareness of choking risk

They may require assistance to:

- Alternate food/fluids
- Control rate and volumes of intake
- Ensure adequate clearance of food and fluids/ prompt multiple swallows
- Use swallowing techniques and strategies
- Stop eating or drinking if there are signs of fatigue

- Choking risk identified
- Client needs to be closely monitored for signs and symptoms of aspiration

It is recommended that all staff with responsibility for providing supervision of clients eating, drinking and swallowing should have received swallowing awareness training.

Additional Notes:

It is acknowledged that some people particularly within ALD settings may not fit neatly into the 3 levels e.g. clients with behaviours that challenge/ autism. Some of these clients may have difficulty tolerating the presence of a staff member in their immediate environment supervising their eating and drinking but nevertheless require some monitoring. In these instances the SLT will provide specific guidance regarding supervision/ support within the individual's bespoke recommendations.

Northern Ireland SLT SQAT April 2016

Appendix 5 - Indicators for Referral to Speech & Language Therapy (SLT) for Eating, Drinking & Swallowing

- Coughing/choking during or after food and/or drink
- Recurrent chest infections or pneumonia.
- Reduction in oral intake leading to weight loss or dehydration with suspected link to swallowing problems.
- Wet or gurgly voice or breath sounds after swallowing.
- Food sticking in the mouth/throat.
- Person complaining of difficulty swallowing.
- Person displaying change in breathing pattern associated with eating or drinking, such as wheezing, breathlessness or increased congestion.
- Change in colour after eating/drinking.
- Inability to control food or saliva in the mouth.
- Increased time to chew food and initiate a swallow.
- Nasal regurgitation (food coming down nose) or reflux can be associated with grimacing or sneezing during eating or drinking.
- Prohibiting/absent oral or pharyngeal reflexes e.g. suck-swallow or bite reflexes.
- Delayed weaning (in children only) in the presence of other factors listed above.

REFERRALS THAT WILL NOT BE ACCEPTED BY SLT

When a person:

- Is stable on previous SLT advice and there has been no change since their last assessment **or** are managing their current diet with no difficulties and not wanting/requiring an upgrade, however where staff are concerned, patients should be re-referred.
- Are currently too medically unfit to eat and drink, please refer when condition improves.
- Have confirmed or suspected oesophageal difficulties with no oral pharyngeal difficulties reported.
- Are refusing **all** food and drink so their swallow cannot be assessed at this time. Please seek medical advice and re-refer when they start to eat or drink if they continue to have difficulties.
- Are having difficulty swallowing medication only, seek advice from pharmacy.

When a child:

- Has difficulty with use or progression of feeding utensils.
- Is a selective eater.
- over packs their mouth
- has a normal developmental weaning pattern such as initial resistance to cup drinking or lumpy foods

*If appropriate, please first check that the person is following the Speech and Language Therapists' previous recommendations. If the person has been following the previous advice and you notice any of the above signs, please contact the relevant Speech & Language Therapy Department to discuss further.

Appendix 6 – example SLT Swallowing Care Plan **Please Check for Local Arrangements**

Belfast Health and Social Care Trust
caring supporting improving together

Speech and Language Therapy Department

ADULT SWALLOWING CARE PLAN

The following recommendations have been made to reduce the risk of chest infections/choking when eating and drinking. Following these recommendations can help reduce but not remove the risk of chest infections or choking. THIS CARE PLAN REPLACES ANY PREVIOUS CARE PLANS PROVIDED.

Speech & Language Therapist: _____ Tel: _____

	LIQUIDS	
☐	LEVEL 0 NORMAL THIN LIQUID	0
☐	LEVEL 1 SLIGHTLY THICK LIQUID	1
☐	LEVEL 2 MILDLY THICK LIQUID	2
☐	LEVEL 3 MODERATELY THICK LIQUID	3
☐	LEVEL 4 EXTREMELY THICK LIQUID	4
	Ensure adequate storage arrangements of thickening agents to prevent accidental eating.	

	FOOD	
☐	LEVEL 7 REGULAR	7
☐	LEVEL 7 REGULAR – EASY TO CHEW	7
☐	LEVEL 6 SOFT & BITE-SIZED	6
☐	LEVEL 5 MINCED & MOIST	5
☐	LEVEL 4 PUREED	4
☐	LEVEL 3 LIQUIDISED	3
☐	BREAD YES/NO	

Further Advice

- ☐ Requires full assistance
- ☐ Prompt to slow down
- ☐ Hand-over-hand support
- ☐ Quiet focused mealtime
- ☐ Ensure good oral hygiene
- ☐ Quiet focused mealtime no talking or moving while eating
- ☐ Support to sit upright
- ☐ Encourage small mouthfuls
- ☐ Check mouth is clear after eating
- ☐ Encourage person to alternate food with liquids

Supervision

- ☐ One to one supervision/support
- ☐ Direct supervision
- ☐ General supervision

Specific instructions/specialised equipment

Monitor chest status closely for any signs of deterioration – please see overleaf. If you are concerned regarding this person's ability to manage these recommendations or require further information please contact the Speech and Language Therapy Department on the above telephone number.

Discussed and agreed with: Patient ☐ Carers ☐ Care Staff ☐ Family ☐ Other ☐

Details of advice leaflets provided: ☐ _____

Refer on to: ☐ _____

Date of next review/discharge: _____ Signed: _____ Date: _____

Copies of care plan provided to: Patient ☐ Family ☐ NH ☐ SW ☐ Day Care ☐ Other ☐

Appendix 6 Continued…..

Belfast Health and Social Care Trust
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Client Details:

Supervision Descriptions

One-to-one supervision – Staff provides full assistance/ one-to- one support and or supervision to an individual client while eating and drinking. This level of supervision may be used with those who require physical prompts/assistance, hand over hand feeding, monitoring and direction regarding eating and drinking recommendations at all times.

Direct supervision - Staff supervises/assists a small number of clients while eating and drinking. This level of supervision may be used to provide verbal prompting, Staff need to observe clients directly at all times

General supervision - Staff supervising the service user plus others in the immediate dining environment i.e. 1 staff member in dining room /feeding environment at all times monitoring all service users eating and drinking. This level of supervision may be used for those whose risk of choking/ aspiration increases due to environmental factors

GUIDANCE FOR CARERS OF PATIENTS WITH SWALLOWING DIFFICULTIES

The following may indicate deterioration in a person's swallowing ability and a reassessment by Speech & Language Therapy (SLT) may be required.

- Coughing/choking during or after food and/or drink
- Recurrent chest infections, or pneumonia
- Reduction in oral intake leading to weight loss or dehydration with suspected link to swallowing problems.
- Wet or gurgly voice/breath sounds after swallowing.
- Food sticking in the mouth/throat.
- Person complaining of difficulty swallowing.
- Person displaying change in breathing pattern associated with eating or drinking, such as wheezing, breathlessness or increased congestion.
- Change in colour after eating/drinking.
- Inability to control food or saliva in the mouth.
- Increased time to chew food and initiate a swallow.
- Nasal regurgitation (food coming down nose)

*Please first check that the person is following the SLT's previous recommendations.
If they have been following the advice and you notice any of the above signs, please contact the relevant SLT Department.
If the patient is still in hospital, please contact the Hospital SLT.
If the patient is in community please contact SLT in the relevant Team or re-refer through call management.

- North & West Call Management: 02890635300
- South & East Call Management: 02890955565.

Appendix 7 - Choosing Medicines for Patients Unable to Take Solid Oral Dose Forms

http://niformulary.hscni.net/Formulary/Adult/specials/Pages/default.aspx

Appendix 8 - Available Training Programmes

Eating, Drinking and Swallowing Training Requirements Matrix

Please note this is a guideline only as knowledge, skills and competencies vary greatly.

Informal EDS training – discussion and demonstration of care plan
Informal training takes places with individuals and people involved in their care to ensure understanding of individual care plans; this may include staff, carers and family.

Level one – EDS eLearning (recommended frequency – repeat every 2 years)

Level one training is to promote awareness of swallowing and the risks associated with EDS difficulties. To help staff identify people who may have difficulties and ensure appropriate onward referral.

- Recommended for all staff who work directly with or prepare food for patients/service users.
- Appropriate for managers and multi-disciplinary team members who make referrals to SLT.
- Useful for staff who have previously attended level 2 training but feel they would benefit from a revision to help build confidence following an EDS incident.
- Benefits new staff that require some awareness while they await level 2 direct training.

You can access Eating, Drinking and Swallowing (EDS) eLearning from the hub eLearning site or click link http://elearning.belfasttrust.local/course/view.php?id=203

'Help Stop Choking' choking awareness DVD is also available from this site.

Level two – Direct Eating, Drinking and Swallowing Awareness Training – includes discussions and practical experience of how to thicken drinks and feed others.
(Recommended frequency – at least every 3 years).

Level two training is recommended for all staff who work with patients/service users with confirmed eating, drinking or swallowing difficulties. To access training, staff should contact their local SLT department.

Aims

- Increase knowledge about the swallowing process.
- Increase knowledge about EDS difficulties – what can go wrong and the consequences.
- Increase confidence in feeding clients with EDS difficulties.
- Increase confidence in using thickeners and modified diets.
- Share experience of working with clients with EDS and how to reduce their risk with feeding.
- Roles and responsibilities.

Guidance on Choking from the Belfast Trust Resuscitation Team

The Resuscitation Council (UK) does not comment on the care of specific individuals and final decisions regarding which treatments are appropriate rest with the multidisciplinary team responsible for care.

General advice for a wheelchair user who is choking:

- This will be individual to the person involved.
- If possible the person choking should be encouraged to cough.
- If this is ineffective the manoeuvre/s used will depend on the individual, the rescuer(s) and the ability of the rescuer(s) to position themselves to undertake the manoeuvre. The general advice would be to undertake backslaps and/or abdominal thrusts if these are possible within the confines of the chair.
- Call for help early as a second or more rescuers can help support the person choking during back slaps or abdominal thrusts.
- If the person becomes unconscious they would need to be laid on a firm surface (floor) and CPR started.

This is what we would teach at present.

The Resuscitation Training Team recommend that if the patient has a severe & multiple Learning Disabilities, the Team looking after that patient will need to contact their medical physician for advice.
Each individual case will have different needs i.e. displacement of heart/lungs, ribs, no sternum which only their doctor may be aware off.

The Resuscitation Team will continue to teach RCUK guidance for choking on our mandatory training sessions"

The Resuscitation Council have very clear guidelines on the treatment of choking which can be accessed by clicking on the following link http://www.resus.org.uk/

The Trust's Resuscitation Officers provide the following programmes:

- In-hospital Life Support (Hospital Staff) – 3 hrs (Adult) 3 Hrs (Paediatrics)
- Community Basic Life Support (Community Staff) – 2 hrs or 3 hrs (with AED)

Please refer the Trust's Statutory/Mandatory Matrix for further details.

The relevant Resuscitation Officer should be contacted in relation to arranging specialised training sessions for particular Service Areas/Patients/Service Users, incorporating Ward based scenarios.

Trust's First Aid Training Policy

The Trust's 3 day First Aid course and 1 day Emergency First Aid course also contains a section on administering first aid to a person who is choking.

Please note that the First Aid at Work Regulations (NI) 1982 make first aid provision for staff who are injured or become ill at work. Link to First Aid Policy below :

http://intranet.belfasttrust.local/policies/Documents/First%20Aid%20at%20Work%20Policy.pdf

Appendix 9 - Example of Good Practice When Someone Is Highlighted As Having a Choking Risk

1. Admission assessment contains trigger question on history of choking e.g. NAPOC, NISAT, About You.

2. Person is highlighted during admission assessment that they have a choking risk.

3. Staff investigate further to gain as much information as possible on past events, swallowing assessments, possible triggers, recommendations etc. and consider referral to relevant members of MDT.

4. This information is then passed on to all staff via communication board and all high risks are discussed at handover.

5. Information is passed to the Catering or Food Provider via phone call or speaking to the cook personally.

6. Risk identified on the menus for the person in question.

7. Person's risk is highlighted on the menu boards with a star.

8. Personal Place Mats or Bedside Swallowing Care Plans are used to highlight choking risk at mealtimes.

9. If a patient is identified as a very high risk then they will be placed on a level of supervision at meals times. A plan of care will be placed in the nursing care plan for all staff to read. This is reviewed a regular intervals or upon need.

10. If there is any change all above is reviewed and amended.

Appendix 10 - Choking Capacity Questions

This tool outlines information that an individual or their carer needs to understand and retain in relation to the risk of choking. It can be completed as a record of someone's understanding in relation to choking, to support capacity assessments and help with management of non-compliance. *(Developed by Helen Cunliffe, Principal Speech & Language Therapist, September 2014).*

	Key concepts
What does the word 'choking' mean?	*(e.g. blockage, food gets stuck in the throat)*
What happens when you choke?	*(e.g. something gets stuck, stops you breathing, you could die)*
What will happen if you stop breathing?	*(e.g. could die, could cause other injury)*
What do you think caused your choking episode(s?)	*(e.g. check for understanding e.g. of any underlying condition)*
Do you think there's a chance that you could choke again?	*(e.g. check for understanding of any potential contributory factors.)*
Can you think of things that might make you choke?	*(e.g. high risk foods for choking, unsafe eating behaviours see also factors which can increase the risk of choking)*
What would you do if you started to choke?	*(e.g. stop eating/call for help)*
What if you are choking and not able to speak or call for help?	(e.g. Lifeline)
What can you do to avoid another choking episode? *(Any visual/written resources required as prompts?)*	*(e.g.) cut food up smaller next time)*

Appendix 11 - Example Bedside Care Plan **Please Check For Local Arrangements**

SWALLOWING RECOMMENDATIONS

Speech and Language Therapy

NAME: _____ DATE: _____

FEEDING ADVICE	• **Alert and upright** • **Monitor chest status** • **Discontinue feeding if any signs of aspiration (coughing/choking/throat clearing/"wet" voice or "wet" breath sounds/pallor change/reduced O2 sats/reduced chest status, etc.)** • **Regular mouthcare / oral hygiene**
LIQUIDS **LEVEL** ☐	
DIET **LEVEL** ☐	
SUPERVISION	
MEDICATION	

If you have any concerns regarding the above, please contact the Speech & Language Therapist on the number below.

Signature: _____
Speech and Language Therapist

March 2019

Appendix 12 - Personal Place Mat

Click here to download of a Placemat Template, with instructions.

Appendix 13 - Link to Hospital Passport

http://www.hscbusiness.hscni.net/pdf/Hospital_Passport_03_17(1).pdf

Appendix 14 - Choking Awareness - Staff Self-Assessment

Use this form to reflect and rate your awareness, knowledge, skills and confidence in identifying people who may have a choking risk and managing that risk. If you score 30, or below, please revise knowledge, e.g. watch the choking awareness DVD available from the eating, drinking and swallowing eLearning. A copy of your completed form can be provided to your manager as evidence of your choking awareness following choking incidents.

Name _____ **Date** _____

Score your awareness, knowledge, skills and confidence from 5 very good to 1 very poor.

	5 Very good I know everything	4 Good I know most things	3 Ok I know some things	2 Poor I know a little	1 Very poor I know very little
1. Do you know what choking is and why people choke?					
2. How would you rate your ability to recognise the signs when someone is choking?					
3. How would you rate your knowledge of the consequences and risks of choking?					
4. How would you rate your knowledge of which foods are high risk choking foods?					
5. How would you rate your skills of knowing how to modify/change food to make it easier to eat?					
6. How would you rate your knowledge of safe eating strategies?					
7. How would you rate your skills of making the environment safer to reduce the risk of choking?					
8. How would you rate your knowledge of the different people who can help someone who has a choking risk?					
9. Are you confident in how to help someone who is choking in an emergency?					
10. Are you confident you know how to support a person who chooses to eat high risk foods?					

Total score /50

Appendix 15 - Help Stop Choking - Choking Awareness Resources

Help reduce the risk of choking by using The Help Stop Choking Website which offers a series of accessible DVD clips, activities, advice leaflets, posters and recording forms available to download for free http://helpstopchoking.hscni.net
.
Also available as an app for apple devices which allows you to work offline, you can meet the person where they are, no need to take them to a computer, ios app Help Stop Choking

Co-developed by BHSCT SLT team with a man with a man who has learning disability, following his own choking experience, the resources aim to empower people to increase their knowledge of choking, safe food choice, eating behaviours and eating environments, first aid and good oral care.

The original choking awareness DVD was Winner of the national Patient Safety and Care Awards 2014 and is available from the BHSCT Eating and Drinking eLearning site and the clips are available to watch from the trust YouTube.

DVD clips include
What is choking?
Change what you eat - make safe food choices
Change the way you eat - encouraging safe eating strategies
Change where you eat – promote safe eating environments,
First aid
The 'Help Stop Choking' awareness song

Choking Advice Leaflets

- Choking awareness book – easy read
- How to reduce the risk of choking - General advice to help someone eat safely and reduce their risk of choking
- General advice for feeding a person with a choking risk
- Choking awareness Looking after your lungs - Useful information and top tips
- Choking awareness Oral health information for carers
- How to reduce the risk of choking General advice to help someone take medications when they have a choking risk
- What to do when a wheelchair user is choking
- Best interest decision – Easy Read
- Capacity and consent – easy Read

Choking awareness posters

- High risk choking foods
- First aid for choking
- Good ideas for a safe room
- Good ideas to keep mouth clean
- Good ideas to slow down
- Good ideas to stop choking

Appendix 16 - Flowchart For follow-up actions and Reporting Following Choking incident

CHOKING INCIDENT
1. Check person treated by appropriate first-aid and follow up medical examination.
2. Inform NOK, GP and other appropriate agencies as necessary
3. Report incident via DATIX Trust internal incident reporting system
4. Complete - Immediate Actions to Consider Following A Choking Event (**Appendix 1).**
5. Consider referral to SLT for a swallowing assessment using indicators **(Appendix 5)**
6. Complete or review care plan and risk assessment - insure controlled measures are in place. Use locally agreed risk form, Trust risk form or **Appendix 2**
7. Discuss episode among staff group- encourage shared learning
8. If care plan has not been followed and were applicable referral to be made to safeguarding in conjunction with your line manager
9. Review staff training (**Appendix 8**)
10. If applicable report to RQIA in conjunction with your line manager
11. Where appropriate consider other people within you care who may be at risk
12. When advised/ when appropriate report to HSE through RIDDOR arrangement

Appendix 17

The Prevention & Management of Patient, Client and Service Users with Identified Choking Risks June 2016 - Easy Read Document

Belfast Health and Social Care Trust
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Reference No: SG 44/11

Title	**Food, Fluid and Nutrition policy – Adult in-patient setting**		
Author(s)	Brona Shaw, Nursing, Governance & Experience, Tel: [redacted] Tony McDonagh, Catering Manager, Tel: [redacted] Irene Thompson, Interim Deputy Director of Nursing Safety, Quality and Patient Experience, Tel: [redacted] Ruth Robb, Infection Prevention Control, Tel: [redacted] Ana Marie Magorrian, Speech and Language, Tel: [redacted] Brenda Nugent, Dietetics, Tel: [redacted] Christine Kelly, Nursing Development Lead, Tel: [redacted] Ann McDonald, Lead Nurse, Mental Health Services, Tel [redacted]		
Ownership:	Brenda Creaney, Nursing and User Experience Director		
Approval by:	Food and Nutrition Policy and Governance Group Standards and Guidelines Committee Executive Team Meeting	**Approval date:**	13/12/2019 09/06/2020 05/08/2020
Operational Date:	August 2020	**Next Review:**	August 2025
Version No.	2	**Supercedes**	V1 – June 2011 – October 2019
Key words:	Nutrition, hydration, malnutrition, dehydration, food, fluid, parenteral nutrition, enteral feeding		
Links to other policies	BHSCT The prevention and management of patient, client, service users with identified choking risks (2019) TP 106/17 BHSCT Food hygiene policy for non-catering staff within all primary and secondary healthcare facilities (2019) SG 21/10 BHSCT Guideline for the translation from national texture descriptors to international dysphagia diet standardised levels (2019) SG 06/19 BHSCT Prioritising the mealtime experience (protected mealtimes) policy (2016) SG 51/15 BHSCT Visitors policy (2019) TP 10/08		

Date	Version	Author	Comments
08/05/2019	1.01	B Shaw	Initial Draft
09/07/2019	1.02	B Shaw	Dietetic Comments IPC Comments Catering
25/07/2019	1.03	B Shaw	Responsibilities and other changes to content
15/08/2019	1.04	B Shaw	Insertion of comments from consultation

03/09/2019	1.05	B Shaw	Insertion of appendices
25/02/2020	1.06	BShaw	Amendement to exemptions 5.3

1.0 INTRODUCTION / PURPOSE OF POLICY

1.1 Background

The link between nutrition and hydration and a person's health is a fundamental part of any stage of life, but all the more so for the sick or vulnerable.

Person-focussed, quality compassionate care involves looking at what matters to a person as a whole, not only concentrating on their specific medical condition.

Malnutrition and dehydration are both causes and consequences of illness, have significant impact on health outcomes and are integral to all care pathways. They can adversely affect clinical outcomes for patients, increases morbidity and mortality, prolong length of stay in healthcare environments and increase costs of care. Malnourished patients in hospital stay longer and are more likely to develop complications or infections.

Although most malnutrition arises in the community setting, once a patient is admitted to hospital, there is a great deal that care providers can do to hasten recovery with close attention to nutrition and hydration needs.

It is a basic human right to be free from thirst or hunger although it is noted that these can sometimes occur in hospital as part of a specific therapy plan.

Hydration

Inadequate hydration can be a common problem in hospitals. Good hydration is important for the safety and wellbeing of hospital patients and medical evidence shows that it can assist in the management of a number of conditions.

Adequate hydration is known to reduce the risk of Urinary Tract Infection (UTI), particularly those infections caused by Gram negative bacteria. Reduction in the risk of UTI has a knock on effect on the risk of developing a Blood Stream Infection (BSI). BSI can be a very serious and patients can become very unwell very quickly. BSI can result in serious adverse outcomes for patients. Reduction in UTI will also help to control the amount of Antibiotics that are used and will help to prevent the development of Antimicrobial resistance.

Malnutrition

Malnutrition, in particular under-nutrition, is a common problem on admission and can increase during a patient's stay. In order to treat the condition it needs to be identified.

Patients identified as having malnutrition will require nutritional support. This can be provided via parenteral nutrition or enteral feeding which may provide total source of nutrition or will be in combination with oral nutritional support

through food fortification and/or with the use of specfic nutritional products. Food fortification should always be considered as the first method to provide nutritional support. When the hospital provide the right food to meet patients' needs for recovery, wound healing and rehabilitation, this can have significant cost savings, as well as delivering a better patient experience.

Patients with dysphagia are at risk of malnourishment due to modification of food and fluids and potential reduction in intake

Malnutition can also apply to the obese patient whose dietary choices are excessive and imbalanced from an energy perspective and therefore lacking in essential nutrients. Poor nutritional status will compromise recovery in obese patients as well as those patients who are undernourished.

The very best nutritional care, delivered with clinical expertise, compassion and humanity, is pivotal to enabling people to stay healthy and to recover from episodes of illness. Central to this is healthcare staff who are skilled at assessing patients' needs; meeting these needs; regularly evaluating plans of care and creating the optimum environment where the best possible practice can occur.

Nutritional screening and appropriate referral can assist in the prevention and treatment of malnutrition. The Trust has adopted the approved screening tool MUST (Malnutrition Universal Screening Tool), in line with Clinical Guidance 32 (NICE 2006) - see Appendix 1.

All clinical staff in the BHSCT play a crucial role in achieving and maintaining excellence in relation to providing adequate food, fluid and nutrition.

1.2 Purpose

This policy has been developed by a multidisciplinary group of professionals to establish best practice with regard to the nutritional support of adult patients.

To ensure all BHSCT staff understand why and how food, fluid and nutritional care requirements of all individuals must be appropriately addressed to enhance nutritional wellbeing and hydration.

To ensure BHSCT staff understand their role and responsibility in relation to food, fluid and nutritional care in supporting individuals to achieve the best possible nutrition and hydration in ways that support optimal wellbeing and which are evidence based.

1.3 Objectives

The BHSCT's principal concern is the delivery of safe and effective food, fluid and nutritional care that ensures the best possible clinical outcomes for individual service users. This can be achieved through ensuring:

- A coordinated and whole-system approach to the delivery of food and fluid by different healthcare professionals that views individual needs and preferences.
- All new staff are familiarised with this policy on commencement of employment.
- All staff are able to access training to enable them to implement the policy as appropriate to their role. It is recommended that new staff receive training within six months of commencement of employment.
- All individuals at greatest risk of malnutrition (over nutrition and undernutrition) are assessed and cared for without prejudice thereby helping to improve the quality of overall clinical care.

2.0 SCOPE OF THE POLICY

This policy applies to all Trust employees who are involved in the provision of food, fluid and nutrition in adult in-patient settings.

This policy relates to BHSCT provision of food, fluid and nutritional care across the life course within hospital settings.

3.0 ROLES/RESPONSIBILITIES

BHSCT recognises the importance and value of effective nutritional care and hydration as an essential part of clinical care, and recognises that it is an integral part of the work of many staff disciplines.
Line managers have a particular role to play in developing a positive culture regarding nutritional care and hydration with staff.

All Trust staff

BHSCT expects the co-operation and involvement of all those working in the food chain (clinical and non-clinical) such as catering, domestic services, medical, nursing, allied health professionals, portering, transport, procurement and managerial staff to promote and support the delivery of safe, quality nutrition and hydration care in adult inpatient settings.

Food And Nutrition Steering Group

The Food and Nutrition Steering Group are responsible for promoting and leading on the strategic design and delivery of quality nutritional care for all those accessing health and social care services within BHSCT through a multi-professional multi-agency approach.

Dietetic Services

Registered Dietitians are responsible for translating the science of nutrition into practical information about food. They work with individuals in different settings to promote nutritional wellbeing, prevent food related problems and treat disease. The BHSCT Dietetic services will be responsible for ensuring:

- That the needs of patients and their carers are at the core of how the Trust delivers its Nutrition and Dietetics Service in accordance with DHSSPS Quality Standards and relevant professional standards and guidelines.
- Structures are in place to support the strategic and operational delivery plans for the achievement of best value Food and Nutritional Care services.
- Structures are in place to support the continuous development, monitoring and reporting of dietetic standards across BHSCT.
- Through appropriate line management structures, the development, achievement, maintenance, monitoring and reporting of agreed service levels and standards are achieved.
- The development, implementation and monitoring of individual nutritional care.
- The provision of therapeutic dietary advice and treatment plans according to medical diagnosis / referral and nutritional assessment / requirements of patients e.g. for renal disease, food allergy, diabetes or conditions that require artificial nutrition support.
- Discharge plans include appropriate nutritional information, and that appropriate nutrition and dietetic support is provided in care settings and the community.

Managers Accountable for Catering Services

Managers Accountable for Catering Services are responsible for the delivery of a safe and effective food and beverage service. They will monitor the catering service and make improvements as necessary, ensuring that staff and systems are compliant with food safety legislation, and lead on the implementation, monitoring and evaluation of the BHSCT Catering Strategy. This includes:

- Controlling the catering budget and establishing contracts for food, beverages and snacks.
- Choosing and ordering ingredients.
- Developing recipes and menus taking into consideration dietetic advice and individuals' age, culture, religion and medical condition.
- Preparing food to approved standards.
- Delivering food to wards, individuals and staff restaurants.
- Maintaining and supervising food hygiene for catering staff.
- Controlling cost and monitoring waste and customer satisfaction.
- Reviewing and developing service delivery.

Medical Staff

Medical staff must play a co-ordinating role between nutritional and other medical and surgical treatments and ensure that individuals receive excellent nutritional screening, assessment and care. This includes:

- Awareness of the protection of patients' mealtimes and the principles or Mealtime Matters.
- Acknowledging the importance of the involvement of all doctors/surgeons in nutritional care and hydration.
- Developing, fostering and encouraging an awareness of the benefits of

appropriate nutritional and hydration management and treatment, before, during and after hospital admission.

- Considering the individual's mental and physical ability to eat, the integrity of gastrointestinal function including motility, digestion and absorption and the metabolism and excretory function in the context of a diagnosis.
- Prescribing treatment, taking into consideration drug nutrient interactions, surgical needs etc.
- Taking note of and applying nutritional screening, and assessing and monitoring nutritional care whilst employing clinical information, and information from biochemistry, haematology and microbiology.
- Deciding, in liaison with the multi-disciplinary team (e.g. nurses, speech & language therapists and dietitians), on the optimal approach to each individual's nutritional and hydration needs and ensuring informed consent.
- Where Patients require oral nutritional supplement products or an oral thickened product, these sould be prescribed on the medical Drug Kardex by Medical staff. See Appendix 7.
- Liaising with individual and individual's relatives e.g. providing a major source of information in respect of all aspects of treatment including nutrition and hydration.
- Leading on ethical decisions in conjunction with the multi-disciplinary team, taking into consideration family and/or carers' views including interpretation of advance directives.
- Nutritional aspects of care in plans for discharge and follow up.
- Nutrition when liaising with primary healthcare professionals.

Ward Sister

Ward Sisters have 24-hour responsibility for the delivery of safe and effective patient care, and will ensure that all nursing staff are compliant with the Food, Fluid and Nutritional Care policy. They will ensure that all nursing staff (as appropriate) are competent in nutrition and hydration risk assessment, the development, implementation and evaluation of nutritional care and discharge plans, and in the provision and of appropriate food and drink for their client group(s).

This includes:

- Ensuring that nursing staff are familiarised with the MUST assessment tool in the Nursing Admission Documentation as part of the induction process.
- Ensuring that nursing staff are competent in the use of the MUST assessment tool.
- Ensuring that the ward or department has weighing scales and a device for measuring height or use the alternative measurements to estimate height as recommended by BAPEN and to ensure that these devices are available, serviced and maintained according to the manufacturer's instructions.
- Ensure that useful resources such as the 'Must Just do it' Flowchart are displayed in ward and department for staff to refer to (Appendix 2)
- Monitor and collate MUST compliance data monthly.

- Provide support to ward staff with those patients needing nutrition support, as part of the MDT. Advising the most appropriate route for patients to meet their short and long term nutrition needs.
- Maintaining an ongoing commitment to delivering optimal nutritional care and hydration.
- Ensuring there is continuous improvement in place in relation to nutritional care.
- Employing routine nutritional screening including assessment of nutritional risk and the ability of the individual to eat and drink.
- Maximising use of available facilities and options to achieve enjoyable, psychosocially beneficial, nutritionally effective meals and food intake.
- Taking responsibility for an individual's food intake and co-ordinating thedelivery of the principles of 'Mealtime Matters' (Appendix 3) at ward level.
- Helping patients with food and drink choices which are in line with their clinical needs.
- Ensuring that nursing staff serve patients the appropriate food and fluids in line with their clinical needs.
- Assisting patients with feeding and drinking as appropriate.
- Monitoring and/or keeping records of food and fluid intake when necessary.
- Being alert to unsafe feeding and drinking practice.
- Being alert to any unsafe weighing and measuring equipment.
- Providing and serving food, and in conjunction with dietitians, supplying oral nutrition supplements.
- Providing expert safe delivery and monitoring of artificial nutritional support.
- Delivering enteral and parenteral nutrition skilfully, closely following standard operating procedures, protocols and guidance.
- Monitoring enteral and parenteral nutrition including fluid balance, blood/urine, glucose, diabetic charts, and microbiology.
- Preventing (cross) infection.
- Liaising with individuals and relatives.
- Employing timely discharge planning and liaising with community staff.

All Registered Nurses and/or Nursing Assistants

The role and remit of the Registered Nurse and/or Nursing Assistant is to:

- Ensure that they familiarise themselves with the MUST assessment tool in the Nursing Admission Documentation as part of their induction process.
- Ensure that they are competent in the use of the MUST assessment tool and use the 'Must Just do it' Flow Chart as a useful resource .
- Ensure the use of ward resources such as weighing scales and a device for measuring height or use the alternative measurements to estimate height as recommended by BAPEN when using the MUST assessment tool.
- Participate in the delivery of the principles of 'Mealtime Matters' at ward level.
- Assist patients with food and drink choices which are in line with their clinical needs.
- Serve the appropriate food and fluids to patients in line with their clinical needs.
- Assist patients with feeding and drinking as appropriate.

- Monitor patients' food/fluid intake.
- Monitor and/or keep records of food and fluid intake when necessary.
- Ensure their practice complies with the Food, Fluid and Nutritional Care policy.
- Support the Nutrition Nurse and Senior Charge Nurse in the improvements in nutritional care and hydration.

All nursing Assistants
The role and remit of the Nursing Assistant is to:
- Participate in the delivery of the principles of 'Mealtime Matters' at ward level.
- Assist patients with food and drink choices which are in line with their clinical needs.
- Serve the appropriate food and fluids to patients in line with their clinical needs.
- Assist patients with feeding and drinking as appropriate.
- Monitor patients' food/fluid intake.
- Monitor and/or keep records of food and fluid intake when necessary.
- Escalate any concerns regarding a patients food or fluid intake to the Nurse in Charge in a timely way.
- Ensure their practice complies with the Food, Fluid and Nutritional Care policy.
- Support the Nutrition Nurse and Senior Charge Nurse in the improvements in nutritional care and hydration.

Nutrition Nurse
The Nutrition Nurses, in conjunction with members of the Nutrition Support Team, assist in the assessment, delivery and monitoring of patients requiring nutritional support, via the parenteral or enteral route, whilst ensuring patient centred care.

They assist in the compiling and implementation of nutritional guidelines for patients receiving parenteral and enteral feeding and take a lead role in the teaching of patients, nursing and other clinical staff in the area of nutrition support**.** They act as a role model for nursing staff in the clinical areas, working with them to demonstrate and promote high standards of nutrition.
This includes:

- Daily review and assessment of patients requiring Parenteral Nutrition.
- Training of patients, carers, Community nurses and nursing staff in the management of Parenteral Nutrition.
- Patient liaison.
- Assessment, troubleshooting, removal and change service for enteral feeding tubes (RIGS, PEGs and JEJ tubes).
- Advise on routes of enteral and parenteral access.
- Participate in local, regional and national development of guidelines, audit, logistic and procurement processes.

Speech and Language Therapist
Speech and language therapists support adults who have dysphagia to eat, drink and swallow safely.
This includes:

- Playing a key role in the diagnosis of dysphagia.

- Helping people regain their swallowing through exercises, techniques and positioning.
- Promoting patient safety through modifying the texture of food and fluids, reducing the risk of malnutrition, dehydration and choking and the service of modified food to patients (Appendix 8, International Dysphagia Diet Standardisation Initiative).
- Promoting quality of life, taking into account an individual's and their families' preferences and beliefs, and helping them adjust to living with swallowing difficulties.
- Working with other healthcare staff, particularly dietitians, to optimise nutrition and hydration.
- Educating and training others in identifying, assessing and managing dysphagia, including families and the wider health and care workforce.

4.0 KEY POLICY PRINCIPLES

Definitions

NICE defines:

Malnutrition as: "a state in which a deficiency of nutrients such as energy, protein, vitamins and minerals causes measurable adverse effects on body composition, function (including social and psychological) and clinical outcome." (NICE, 2012)

Dehydration as: "a state in which a relative deficiency of fluid causes adverse effects on function and clinical outcome. In the elderly being short of fluid is far more common, results from limited fluid intake, and is reflected in raised osmolality".

Key Policy Statement(s)

- All patients will be screened on admission or at an appropriate opportunity, within 24 hours, to assess their nutritional status, using Malnutrition Universal Screening Tool (MUST).

  The following are exempt:
  - All dialysis patients admitted to BCH (already under the dietitian care.)
  - All patients admitted on enteral feeding (refer to dietitian on admission).
  - All patients admitted on parenteral feeding (refer to dietitian on admission).
  - All patients in ICU.

- Robust plans of care will be developed for those deemed at nutritional risk. These will include advice and support by appropriate members of MDT.

- All patients remaining in hospital for more than one week will be re-screened as per MUST. Malnutrition Universal Screening Tool – BAPEN https://www.bapen.org.uk/pdfs/must/must-full.pdf See Appendix 4

- Within a palliative care context it may not be in the patient's best interest to weigh him/her on a weekly basis as this may only serve to reinforce the

unavoidable anorexia and cachexia often experienced with advanced, incurable disease.

- When a patient is on a nutritional plan of care, weekly weights may be indicated to monitor outcomes.

- Patients found to be at low risk of malnutrition will be offered the normal menu including snacks and beverages appropriate to their cultural and religious requirements. This will be implemented by nursing staff at ward level.

- Patients requiring a special therapeutic diet should be placed on the appropriate menu where available and referred to the dietitian, when indicated.

- Catering department should be notified about the needs of patients who require a special diet based on cultural/religious beliefs.

- Appropriately modified or fortified diet or oral nutritional supplements will be available for patients who require these, following assessment by Speech and Language Therapist and Dietitian.

- The dietitian will liaise with all relevant healthcare professionals ensuring that nursing, medical, catering and pharmaceutical staff are informed of any specific dietary requirements.

- Food will be nutritious and served by nursing staff in an appropriate and appetising manner.

- All food preparation will comply with food safety legislation.

A **protected meal time policy** will be applied across the Trust to allow patients to eat without interruption.

- All staff to be aware of and adhere to the Protected Mealtime policy and the principles of Mealtime Matters .

- Non-urgent activities such as cleaning, non-priority treatments, ward rounds, investigations visiting etc. to be designed to operate around and outside of pre-set meal times.

- Staff and visitors respect the patients' mealtimes as a time focused on the patient.

- Family /carers who **are** offering support and assistance to the patient are encouraged and permitted to be present at mealtimes.

- Where a written sign is used at the bed or on the whiteboard to indicate a special diet, the description must be appropriate and preserve the patient's dignity and privacy at all times.

- The nurse-in charge will be responsible for ensuring patients are offered assistance when needed in choosing from the menu whilst ensuring the preferences of individual patients are respected.

- Where appropriate, toileting and/or hand hygiene facilities will be made available before and after meals.

- The nurse-in charge will be responsible for ensuring an environment conducive to eating in a calm and un-hurried manner.

- The nurse-in-charge will ensure that adequate preparation is made before meals; the patient is ready to eat in a safe and comfortable position and food is within reach.

- In keeping with the principles in the "Get your 10 a Day, The Nursing Care Standards for Patient Food in Hospital" (Appendix 5) those patients who require support with eating and drinking will be identified using a clear system of identifying such patients e.g. coloured napkin/coloured tray; and they will receive assistance when it is required.

- The nurse-in-charge will allocate a member of the team to assist patients who require help with eating and drinking, ensuring the availability of specially adapted equipment and assistance with condiments etc where required. This will be undertaken in a manner commensurate with their needs and dignity.

- The nurse-in-charge will ensure that oral hygiene and denture care needs have been met.

- Where a patient has been identified as at risk of malnutrition, the meal tray will not be removed until intake has been observed and documented by a member of staff.

- Standardised food and fluid charts will be utilised to document fluid and nutritional intake in those patients deemed at hydration or nutritional risk.

- Where a patient's meal is missed, the patient will be offered an alternative meal or snack as near to the meal time as possible.

- Where clinically appropriate, the patient will have access to fresh drinking water or modified fluids at all times.

- Relatives/carers who wish to provide support and assistance at meal times can do so following agreement with the nurse-in-charge.

- The nurse-in-charge must ensure ongoing engagement with patients and carers about the mealtime experience and any nutritional concerns identified.

- Patients in the Emergency Department pending admission will receive a hot meal. Special dietery/religious requirements need to be requested from the Catering Department on a one to one basis.

- Patients who have been discharged but are remaining on the ward until their transport/carer arrangements are in place will receive a hot meal. Special dietery/religious requirements need to be requested from the Catering Department on a one to one basis.

- Any special dietary requirements or nutritional risks will be identified and will form an obligatory part of any medical/nursing discharge summary. This information will be reported to any relevant healthcare professional in the community and carers of the patient.

- On discharge from hospital, if a patient is recieving oral nutritional supplement products or an oral thickened product, this must be entered onto the patients discharge letter.
  Patients should be provided with a 3 -7 day supply of these products from the ward on discharge.

Policy Principles

4.1 All Trust staff should be aware of their role and responsibilities around the provision in relation to food, fluid and nutritional care.

5.0 IMPLEMENTATION OF POLICY

5.1 Dissemination

All Trust staff who have involvement or are working in the food chain (clinical and non-clinical) such as catering, domestic services, medical, nursing, allied health professionals, portering, transport, procurement and managerial staff

The BHSCT Food and Nutrition Steering Group should be notified if there are significant barriers and timescales which are not being met.

5.2 Resources

Resources to support the implementation of this policy can be found at https://www.bapen.org.uk/pdfs/must/must-full.pdf

5.3 Exceptions

6.0 MONITORING

Adherence to the policy will be monitored by regular audits and through the use of the Mealtime Matters Observation Toolkit, patient feedback and complaints.

7.0 EVIDENCE BASE / REFERENCES

For patient catering

- 10 key characteristics of good nutrition care and hydration, NHS England (Appendix 6)
- Nutrition and Hydration Digest, The British Dietetic Association
- Malnutrition Universal Screening Tool or equivalent1 (BAPEN)
- Promoting Good Nutrition - A Strategy for good nutritional care for adults in all care settings in Northern Ireland 2011-2016

For all catering

- Food Safety (Northern Ireland) Order 1991,
- the General Food Law Regulation (EC) 178/2002,
- the General Food Regulations (Northern Ireland) 2004,
- the Food Hygiene Regulations (Northern Ireland) 2006
- Food Standards Act 1999.

8.0 CONSULTATION PROCESS

- Patient & Client Support Services/ Catering Team
- Infection Prevention and Control Team
- Central Nursing Team
- Divisional Nursing Team
- Dietician Trust Lead
- Learning Disability Team

9.0 APPENDICES / ATTACHMENTS

Appendix 1 Malnutrition Universal Screening Tool (MUST)
Appendix 2 'Must just do it' Flow Chart
Appendix 3 'Mealtime Matters'
Appendix 4 Bapen resources
Appendix 5 Department of Health Social Services and Public Safety Northern Ireland. Get Your 10 a Day! The Nursing Care Standards for Patient Food in Hospitals. 2007. DHSSPS, Belfast.
Appendix 6 10 key characteristics of 'good nutrition and hydration care'. NHS England
Appendix 7 Recording Oral Nutritional Supplements and action on Discharge
Appendix 8 International Dysphagia Diet Standardisation Initiativecording Oral Nutritional Supplements and action on Discharge

10.0 EQUALITY STATEMENT

In line with duties under the equality legislation (Section 75 of the Northern Ireland Act 1998), Targeting Social Need Initiative, Disability discrimination

and the Human Rights Act 1998, an initial screening exercise to ascertain if this policy should be subject to a full impact assessment has been carried out. The outcome of the Equality screening for this policy is:

Major impact ☐

Minor impact ☐

No impact. ☒

11.0 DATA PROTECTION IMPACT ASSESSMENT

New activities that involve collecting and using personal data can result in privacy risks. In line with requirements of the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 the Trust has to consider the impacts on the privacy of individuals and ways to mitigate against the risks. Where relevant an initial screening exercise should be carried out to ascertain if this policy should be subject to a full impact assessment (see Appendix 7). The guidance for conducting a Data Protection Impact Assessments (DPIA) can be found via this **link.**
The outcome of the DPIA screening for this policy is:

Not necessary – no personal data involved ☐

A full data protection impact assessment is required ☐

A full data protection impact assessment is not required ☒

If a full impact assessment is required the author (Project Manager or lead person) should go ahead and begin the process. Colleagues in the Information Governance Team will provide assistance where necessary.

12.0 RURAL IMPACT ASSESSMENTS

From June 2018 the Trust has a legal responsibility to have due regard to rural needs when developing, adopting, implementing or revising policies, strategies and plans, and when designing and delivering public services.
It is your responsibility as policy or service lead to consider the impact of your proposal on people in rural areas – you will need to refer to the shortened rural needs assessment template and summary guidance on the Belfast Trust Intranet. Each Directorate/Division has a Rural Needs Champion who can provide support/assistance in this regard if necessary.

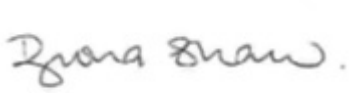
13.0 REASONABLE ADJUSTMENTS ASSESSMENT

Under the Disability Discrimination Act 1995 (DDA) (as amended), all staff/service providers have a duty to make **Reasonable Adjustments** to any

barrier that a person with a disability faces when accessing or using goods, facilities and services, in order to remove or reduce such barriers. For example, physical access, communicating with people who have a disability, producing information such as leaflets or letters in accessible/alternative formats e.g. Easy Read, Braille, or Audio or being more flexible regarding appointments . This is a non-delegable duty. This policy has been developed in accordance with the Trust's legal duty to consider the need to make reasonable adjustments under the DDA.

SIGNATORIES

(Policy – Guidance should be signed off by the author of the policy and the identified responsible director).



13/12/2019

_____ **Date:** _____

Author



05/08/2020

_____ **Date:** _____

Director

Appendix 1: Malnutrition Universal Screening Tool

Malnutrition Universal Screening Tool (MUST)

To identify those adults who are at risk of malnourishment or who are malnourished

	BMI	Date / Time	Height: _____ ☐ Actual ☐ Recalled ☐ Unable to measure / recall Reason: _____	Weight: _____ ☐ Actual ☐ Recalled ☐ Unable to weigh / recall Reason: _____

Step 1: BMI score - BMI kg/m2		Score
Over 20 (over 30 obese)	0	
18.5 to 20	1	
Less than 18.5	2	

If unable to calculate BMI: Estimating BMI category can be done from Mid Upper Arm Circumference (MUAC)
MUAC less than 23.5 BMI likely < 20 MUAC greater than 32.0cm BMI likely > 30

Step 2: weight loss score unplanned weight loss in last 3 – 6 months		
Less than 5%	0	
Between 5 – 10%	1	
More than 10%	2	
Step 3: acute disease effect score		
If the Person is acutely ill and there has been, or is likely to be no nutritional intake for more than 5 days	2	
Total MUST score		

Low Risk = 0	Medium Risk = 1	High Risk ≥ 2

Malnutrition Universal Screening Tool (MUST) flowchart

Low risk - MUST score = 0	Medium risk - MUST score = 1	High risk - MUST score ≥ 2
• Record MUST details • Recommend a well balanced diet	• Record MUST details • Recommend high protein/energy diet • Monitor intake for 3 days (record on food chart)	• Record MUST details • Refer to dietitian • Recommend high protein/energy diet • Monitor intake as per dietician (record on food chart)
Rescreen Weekly	Rescreen 1 Week and refer to dietitian if risk status changes	

Eating and drinking

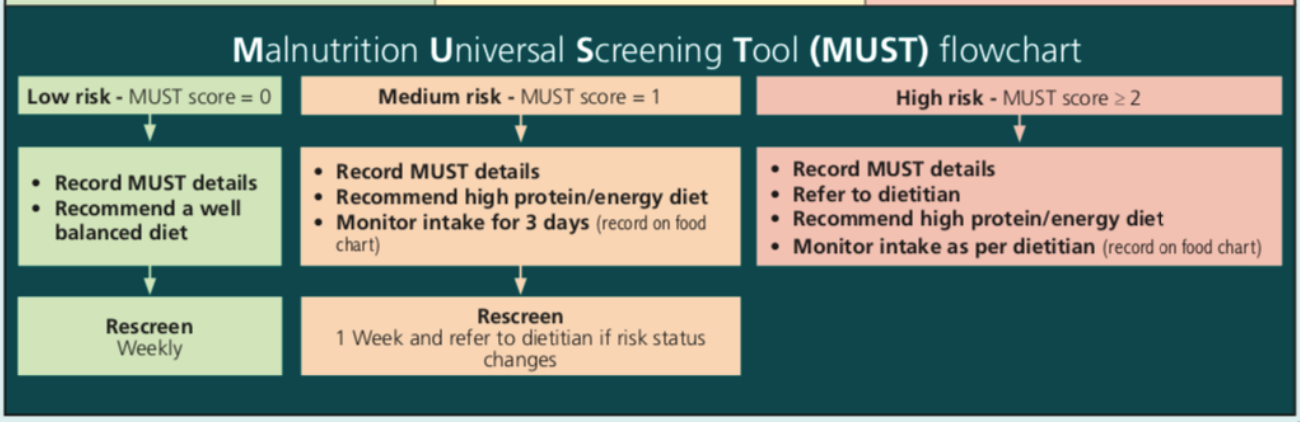
Person – All About Me	Assessment
Able to eat and drink: ☐ Independently ☐ Help required ☐ Full assistance Difficulty swallowing: ☐ Yes ☐ No Appetite: ☐ Good ☐ Fair ☐ Poor Appetite change: ☐ Yes ☐ No Dietary Requirements/Modifications including preferences: Food intolerances: Do you wear dentures: ☐ Yes ☐ No Top present: ☐ Yes ☐ No Bottom present: ☐ Yes ☐ No Secure fitting: ☐ Yes ☐ No Diabetes: ☐ Type1 ☐ Type 2 ☐ None Controlled by: ☐ Diet ☐ Tablet ☐ Hormone ☐ Insulin Other: _____	Nil by mouth ☐ Yes ☐ No Last ate: _____ Last drank: _____ Enteral feeding: ☐ Yes ☐ No Type of feed: Regime: Route/ Device type: Size: Frequency of change: Date next change due: Are you taking oral steroids: ☐ Yes ☐ No Do you wish to be involved in your insulin administration: ☐ Yes ☐ No ☐ NA If Yes, Person able and agrees to administer insulin under supervision: ☐ Yes

6

Malnutrition Universal Screening Tool (MUST)

To identify those adults who are at risk of malnourishment or who are malnourished

		Date:	Date:	Date:
		Time:	Time:	Time:
		Signature:	Signature:	Signature:
		Height:	Height:	Height:
		Weight:	Weight:	Weight:
		BMI:	BMI:	BMI:
Step 1: BMI score - BMI kg/m2		Score:	Score:	Score:
Over 20 (over 30 obese)	0			
18.5 to 20	1			
Less than 18.5	2			
If unable to calculate BMI: Estimating BMI category can be done from Mid Upper Arm Circumference (MUAC) MUAC less than 23.5 BMI likely <20 MUAC greater than 32.0cm BMI likely > 30				
Step 2: weight loss score unplanned weight loss in last 3 – 6 months				
Less than 5%	0			
Between 5 – 10%	1			
More than 10%	2			
Step 3: acute disease effect score				
If the Person is acutely ill and there has been, or is likely to be no nutritional intake for more than 5 days	2			
Total MUST score				
Low Risk = 0	Medium Risk = 1		High Risk ≥ 2	



Appendix 2: ‘Must Just do it’ Flowchart

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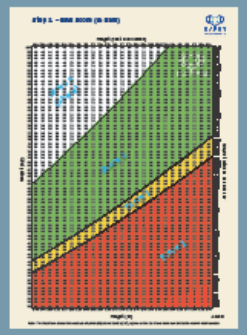
BT Mod 3 Witness Stmt 20 Mar 2023 PART 6 OF 9 Exhibit Bundle (5 of 8) (T09)
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MUST Just do it

Belfast Health and Social Care Trust
caring supporting improving together

Step 1
BMI score

BMI kg/m2	Score
>20 (>30 Obese)	0
18.5 -20	1
<18.5	2



Step 2
Weight loss score

Unplanned weight loss in past 3-6 months	
%	Score
<5	0
5-10	1
>10	2



Step 3
Establish acute disease effect and score

If patient is acutely ill **and** there has been or is likely to be no nutritional intake for >5 days

Score 2

If unable to obtain height and weight, see resource folder for alternative measurements and use of subjective criteria.

Acute disease effect is unlikely to apply outside hospital. See 'MUST' Explanatory Booklet for further information

Step 4 Overall risk of malnutrition

Add Scores together to calculate overall risk of malnutrition

Score 0 Low Risk	Score 1 Medium Risk	Score 2 or more High Risk

Step 5 Management guidelines

0 = Low Risk
Routine clinical care

- Repeat screening
- Hospital – weekly Care Homes – monthly Community – annually for special groups
- e.g. those >75 yrs

1 = Medium Risk
Observe

- Document dietary intake for 3 days
- If adequate – little concern and repeat screening
- Hospital – weekly
- Care Home – at least monthly Community – at least every 2-3 months
- If inadequate – clinical concern
- – follow local policy, set goals, improve and increase overall nutritional intake, monitor and review care plan regularly

2 or more
High Risk
Treat*

- Refer to dietitian, Nutritional Support Team or implement local policy
- Set goals, improve and increase overall nutritional intake
- Monitor and review care plan Hospital – weekly
- Care Home – monthly Community – monthly
- *Unless detrimental or no benefit is expected from nutritional support e.g. imminent death.

For further information refer to Resource folder
Ref. BAPEN

Pamela Moore, Sharon Holmes, Brenda Nugent and Linda Crozier

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Appendix 3: ‘Mealtime Matters’

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Belfast Health and Social Care Trust

Before Mealtimes

Nursing staff must ensure:

- SALT and Dietetic requirements of all patients are considered.
- The Catering Department is notified of special diets before 10am.
- Patients are offered choice at time of meal service.
- A registered nurse is nominated to act as Meal Supervisor on every shift.
- The environment is clean, bright and fresh.
- All patients are comfortable and sitting upright.
- Meal provision has been made for any patients not present for mealtime.

Staff with Catering responsibilities

- To alert nursing staff/ Meal Supervisor that meal times will commence in five minutes
- Ensure food temperatures are checked in line with Food Safety requirements.

Staff member responsible for the service of beverages

- Liaise with Meal Supervisor /registered nurse to ensure support is provided to patients who require their drinks to be thickened or to identify patients who are Nil by Mouth.
- Ensure all staff must wash their hands and wear protective apron prior to meal service.



mealmatters

'Caring and supporting together at mealtimes'

During Mealtimes

Nursing Staff must ensure:

- Staff are available to assist with mealtimes.
- Patients receive the correct meal and any dietary requirements are met.
- Adapted plates/cutlery and protective napkin are provided where required.
- Mealtimes are not interrupted by staff.
- Focus on one patient at a time where assisted feeding is required.
- Alternatives are offered to a patient who refuses their meal.

Staff with Catering responsibilities must :

- They take direction from the Meal Supervisor with mealtime coordination responsibility.
- Serve food in correct portion size as ordered.
- Present food attractively.
- Ensure any accompanying condiments are available and help to open these if required.
- Draw attention to nursing staff if a patient does not eat their meal.

After Mealtimes

Staff with Catering responsibilities must:

- Before clearing tray table check with the mealtime coordinator if anyone requires any more to eat or drink.

Nursing Staff must ensure:

- Meal Supervisor must scan the ward to ensure all patients have had enough to eat and drink and received assistance where required.
- Patients are satisfied with their meal and communicate any issues to Catering supervisor/ manager where appropriate.
- The Patient area is cleared and cleaned.
- The Patient intake recorded as is appropriate.



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Appendix 4: Bapen Resources Please visit: https://www.bapen.org.uk/pdfs/must/must-full.pdf

BAPEN
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'Malnutrition Universal Screening Tool'

MAG
Malnutrition Advisory Group
A Standing Committee of BAPEN

BAPEN is registered charity number 1023927 www.bapen.org.uk

'MUST'

'MUST' is a five-step screening tool to identify **adults,** who are malnourished, at risk of malnutrition (undernutrition), or obese. It also includes management guidelines which can be used to develop a care plan.

It is for use in hospitals, community and other care settings and can be used by all care workers.

This guide contains:

- A flow chart showing the 5 steps to use for screening and management
- BMI chart
- Weight loss tables
- Alternative measurements when BMI cannot be obtained by measuring weight and height.

The 5 'MUST' Steps

Step 1

Measure height and weight to get a BMI score using chart provided. *If unable to obtain height and weight, use the alternative procedures shown in this guide.*

Step 2

Note percentage unplanned weight loss and score using tables provided.

Step 3

Establish acute disease effect and score.

Step 4

Add scores from steps 1, 2 and 3 together to obtain overall risk of malnutrition.

Step 5

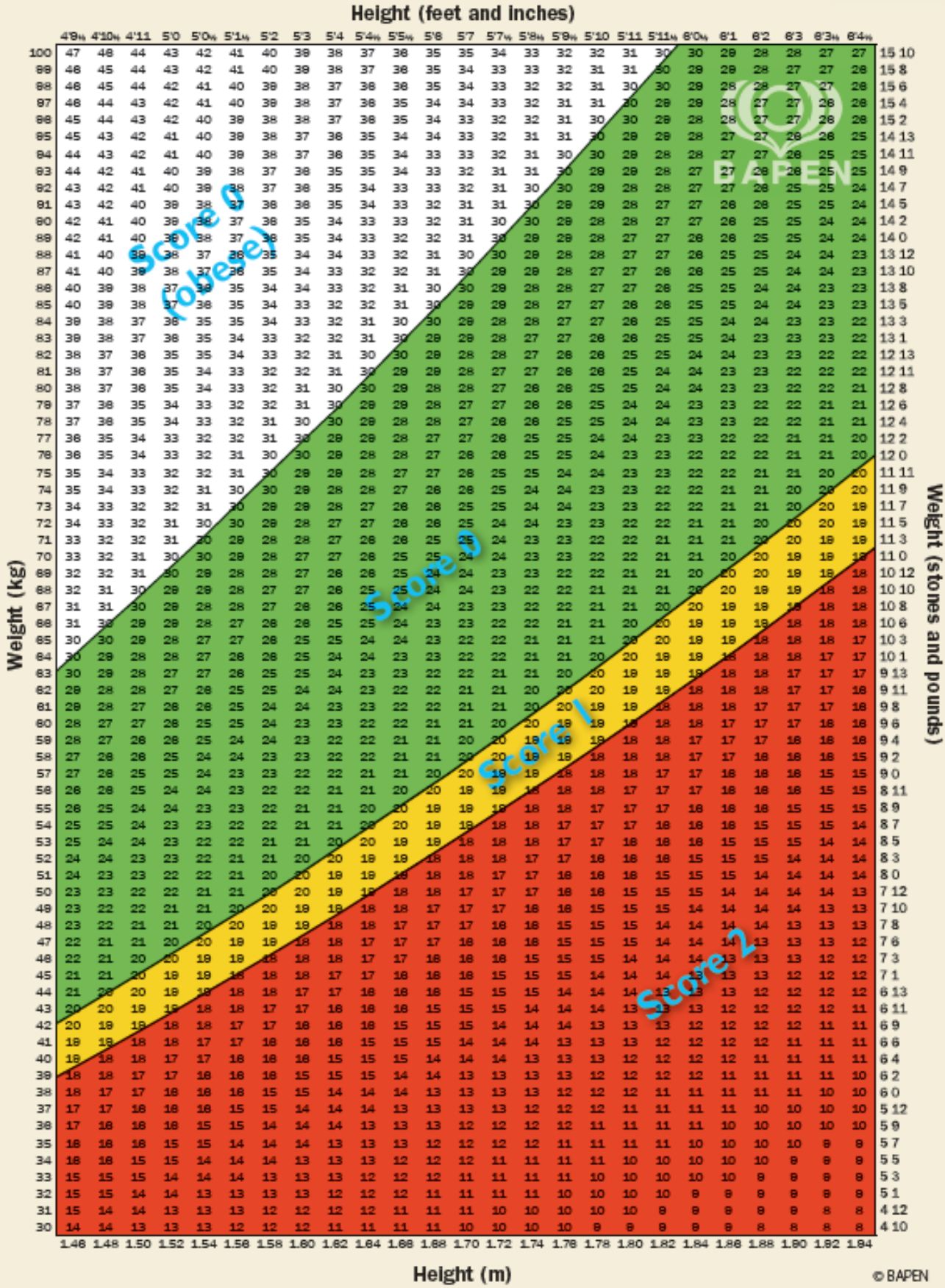
Use management guidelines and/or local policy to develop care plan.

Please refer to *The 'MUST' Explanatory Booklet* for more information when weight and height cannot be measured, and when screening patient groups in which extra care in interpretation is needed (e.g. those with fluid disturbances, plaster casts, amputations, critical illness and pregnant or lactating women). The booklet can also be used for training. See *The 'MUST' Report* for supporting evidence. Please note that 'MUST' has not been designed to detect deficiencies or excessive intakes of vitamins and minerals and is of **use only in adults.**

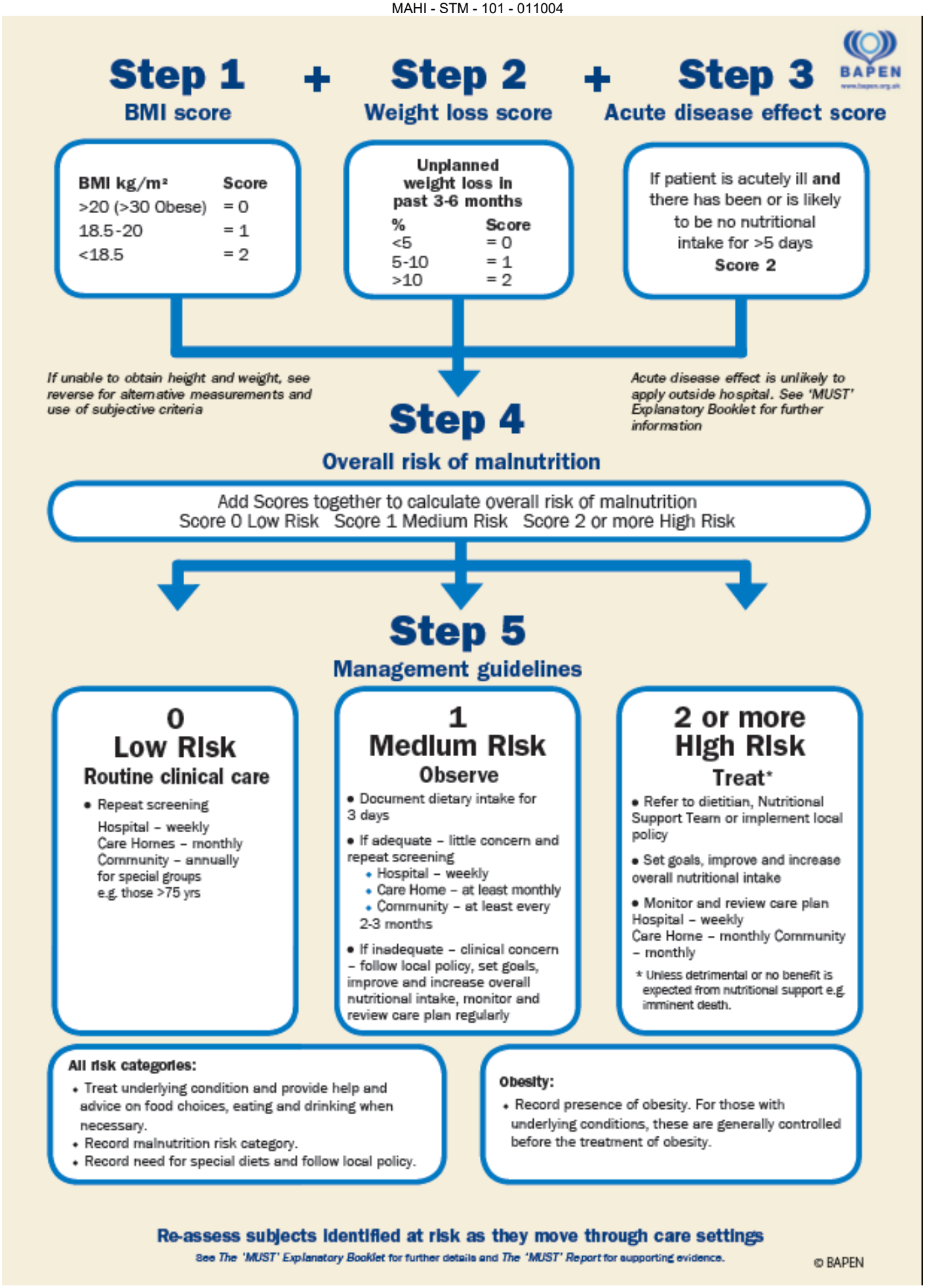
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Step 1 – BMI score (& BMI)

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Note : The black lines denote the exact cut off points (30,20 and 18.5 kg/m^2), figures on the chart have been rounded to the nearest whole number.


Step 1
BMI score
+
Step 2
Weight loss score
+
Step 3
Acute disease effect score
BAPEN
BMI kg/m²
Score
>20 (>30 Obese) = 0
18.5-20 = 1
<18.5 = 2
Unplanned weight loss in past 3-6 months
%
Score
<5 = 0
5-10 = 1
>10 = 2
If patient is acutely ill and there has been or is likely to be no nutritional intake for >5 days
Score 2
If unable to obtain height and weight, see reverse for alternative measurements and use of subjective criteria
Acute disease effect is unlikely to apply outside hospital. See 'MUST' Explanatory Booklet for further information
Step 4
Overall risk of malnutrition
Add Scores together to calculate overall risk of malnutrition
Score 0 Low Risk Score 1 Medium Risk Score 2 or more High Risk
Step 5
Management guidelines
0
Low Risk
Routine clinical care
• Repeat screening
Hospital – weekly
Care Homes – monthly
Community – annually
for special groups
e.g. those >75 yrs
1
Medium Risk
Observe
• Document dietary intake for 3 days
• If adequate – little concern and repeat screening
◦ Hospital – weekly
◦ Care Home – at least monthly
◦ Community – at least every 2-3 months
• If inadequate – clinical concern – follow local policy, set goals, improve and increase overall nutritional intake, monitor and review care plan regularly
2 or more
High Risk
Treat*
• Refer to dietitian, Nutritional Support Team or implement local policy
• Set goals, improve and increase overall nutritional intake
• Monitor and review care plan
Hospital – weekly
Care Home – monthly Community – monthly
* Unless detrimental or no benefit is expected from nutritional support e.g. imminent death.
All risk categories:
• Treat underlying condition and provide help and advice on food choices, eating and drinking when necessary.
• Record malnutrition risk category.
• Record need for special diets and follow local policy.
Obesity:
• Record presence of obesity. For those with underlying conditions, these are generally controlled before the treatment of obesity.
Re-assess subjects identified at risk as they move through care settings
See The 'MUST' Explanatory Booklet for further details and The 'MUST' Report for supporting evidence.
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Step 2 – Weight loss score

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	Score 0 Wt loss < 5%	Score 1 Wt loss 5 - 10%	Score 2 Wt loss > 10%
	Weight loss in last 3 to 6 months		
Current weight kg	Less than (kg)	Between (kg)	More than (kg)
30	1.6	1.6 - 3.3	3.3
31	1.6	1.6 - 3.4	3.4
32	1.7	1.7 - 3.6	3.6
33	1.7	1.7 - 3.7	3.7
34	1.8	1.8 - 3.8	3.8
35	1.8	1.8 - 3.9	3.9
36	1.9	1.9 - 4.0	4.0
37	1.9	1.9 - 4.1	4.1
38	2.0	2.0 - 4.2	4.2
39	2.1	2.1 - 4.3	4.3
40	2.1	2.1 - 4.4	4.4
41	2.2	2.2 - 4.6	4.6
42	2.2	2.2 - 4.7	4.7
43	2.3	2.3 - 4.8	4.8
44	2.3	2.3 - 4.9	4.9
45	2.4	2.4 - 5.0	5.0
46	2.4	2.4 - 5.1	5.1
47	2.5	2.5 - 5.2	5.2
48	2.5	2.5 - 5.3	5.3
49	2.6	2.6 - 5.4	5.4
50	2.6	2.6 - 5.6	5.6
51	2.7	2.7 - 5.7	5.7
52	2.7	2.7 - 5.8	5.8
53	2.8	2.8 - 5.9	5.9
54	2.8	2.8 - 6.0	6.0
55	2.9	2.9 - 6.1	6.1
56	2.9	2.9 - 6.2	6.2
57	3.0	3.0 - 6.3	6.3
58	3.1	3.1 - 6.4	6.4
59	3.1	3.1 - 6.6	6.6
60	3.2	3.2 - 6.7	6.7
61	3.2	3.2 - 6.8	6.8
62	3.3	3.3 - 6.9	6.9
63	3.3	3.3 - 7.0	7.0
64	3.4	3.4 - 7.1	7.1

	Score 0 Wt loss < 5%	Score 1 Wt loss 5 - 10%	Score 2 Wt loss > 10%
	Weight loss in last 3 to 6 months		
kg	Less than (kg)	Between (kg)	More than (kg)
65	3.4	3.4 - 7.2	7.2
66	3.5	3.5 - 7.3	7.3
67	3.5	3.5 - 7.4	7.4
68	3.6	3.6 - 7.6	7.6
69	3.6	3.6 - 7.7	7.7
70	3.7	3.7 - 7.8	7.8
71	3.7	3.7 - 7.9	7.9
72	3.8	3.8 - 8.0	8.0
73	3.8	3.8 - 8.1	8.1
74	3.9	3.9 - 8.2	8.2
75	3.9	3.9 - 8.3	8.3
76	4.0	4.0 - 8.4	8.4
77	4.1	4.1 - 8.6	8.6
78	4.1	4.1 - 8.6	8.7
79	4.2	4.2 - 8.7	8.8
80	4.2	4.2 - 8.9	8.9
81	4.3	4.3 - 9.0	9.0
82	4.3	4.3 - 9.1	9.1
83	4.4	4.4 - 9.2	9.2
84	4.4	4.4 - 9.3	9.3
85	4.5	4.5 - 9.4	9.4
86	4.5	4.5 - 9.6	9.6
87	4.6	4.6 - 9.7	9.7
88	4.6	4.6 - 9.8	9.8
89	4.7	4.7 - 9.9	9.9
90	4.7	4.7 - 10.0	10.0
91	4.8	4.8 - 10.1	10.1
92	4.8	4.8 - 10.2	10.2
93	4.9	4.9 - 10.3	10.3
94	4.9	4.9 - 10.4	10.4
95	5.0	5.0 - 10.6	10.6
96	5.1	5.1 - 10.7	10.7
97	5.1	5.1 - 10.8	10.8
98	5.2	5.2 - 10.9	10.9
99	5.2	5.2 - 11.0	11.0

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Alternative measurements and considerations

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Step 1: BMI (body mass index)

If height cannot be measured

- Use recently documented or self-reported height (if reliable and realistic).
- If the subject does not know or is unable to report their height, use one of the alternative measurements to estimate height (ulna, knee height or demispan).

Step 2: Recent unplanned weight loss

If recent weight loss cannot be calculated, use self-reported weight loss (if reliable and realistic).

Subjective criteria

If height, weight or BMI cannot be obtained, the following criteria which relate to them can assist your professional judgement of the subject's nutritional risk category. Please note, these criteria should be used collectively not separately as alternatives to steps 1 and 2 of 'MUST' and are not designed to assign a score. Mid upper arm circumference (MUAC) may be used to estimate BMI category in order to support your overall impression of the subject's nutritional risk.

1. BMI

- Clinical impression – thin, acceptable weight, overweight. Obvious wasting (very thin) and obesity (very overweight) can also be noted.

2. Unplanned weight loss

- Clothes and/or jewellery have become loose fitting (weight loss).
- History of decreased food intake, reduced appetite or swallowing problems over 3-6 months and underlying disease or psycho-social/physical disabilities likely to cause weight loss.

3. Acute disease effect

- Acutely ill and no nutritional intake or likelihood of no intake for more than 5 days.

Further details on taking alternative measurements, special circumstances and subjective criteria can be found in *The 'MUST' Explanatory Booklet*. A copy can be downloaded at www.bapen.org.uk or purchased from the BAPEN office. The full evidence-base for 'MUST' is contained in *The 'MUST' Report* and is also available for purchase from the BAPEN office.

BAPEN Office, Secure Hold Business Centre, Studley Road, Redditch, Worcs, B98 7LG. Tel: 01527 457 850. Fax: 01527 458 718. bapen@sovereignconference.co.uk BAPEN is registered charity number 1023927. www.bapen.org.uk

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'MUST' is supported by the British Dietetic Association, the Royal College of Nursing and the Registered Nursing Home Association.

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Alternative measurements: Instructions and tables

If height cannot be obtained, use length of forearm (ulna) to calculate height using tables below.
(See The 'MUST' Explanatory Booklet for details of other alternative measurements (knee height and demispan) that can also be used to estimate height).

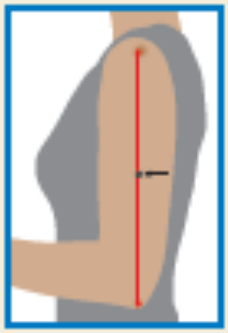
Estimating height from ulna length



Measure between the point of the elbow (olecranon process) and the midpoint of the prominent bone of the wrist (styloid process) (left side if possible).

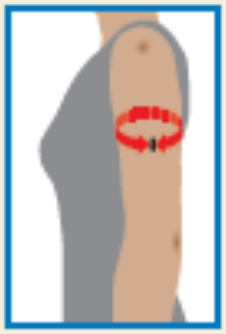
Height (m)	men (<65 years)	1.94	1.93	1.91	1.89	1.87	1.85	1.84	1.82	1.80	1.78	1.76	1.75	1.73	1.71
	men (≥65 years)	1.87	1.86	1.84	1.82	1.81	1.79	1.78	1.76	1.75	1.73	1.71	1.70	1.68	1.67
	Ulna length (cm)	32.0	31.5	31.0	30.5	30.0	29.5	29.0	28.5	28.0	27.5	27.0	26.5	26.0	25.5
Height (m)	Women (<65 years)	1.84	1.83	1.81	1.80	1.79	1.77	1.76	1.75	1.73	1.72	1.70	1.69	1.68	1.66
	Women (≥65 years)	1.84	1.83	1.81	1.79	1.78	1.76	1.75	1.73	1.71	1.70	1.68	1.66	1.65	1.63
Height (m)	men (<65 years)	1.69	1.67	1.66	1.64	1.62	1.60	1.58	1.57	1.55	1.53	1.51	1.49	1.48	1.46
	men (≥65 years)	1.65	1.63	1.62	1.60	1.59	1.57	1.56	1.54	1.52	1.51	1.49	1.48	1.46	1.45
	Ulna length (cm)	25.0	24.5	24.0	23.5	23.0	22.5	22.0	21.5	21.0	20.5	20.0	19.5	19.0	18.5
Height (m)	Women (<65 years)	1.65	1.63	1.62	1.61	1.59	1.58	1.58	1.55	1.54	1.52	1.51	1.50	1.48	1.47
	Women (≥65 years)	1.61	1.60	1.58	1.56	1.55	1.53	1.52	1.50	1.48	1.47	1.45	1.44	1.42	1.40

Estimating BMI category from mid upper arm circumference (MUAC)



The subject's left arm should be bent at the elbow at a 90 degree angle, with the upper arm held parallel to the side of the body. Measure the distance between the bony protrusion on the shoulder (acromion) and the point of the elbow (olecranon process). Mark the mid-point.

Ask the subject to let arm hang loose and measure around the upper arm at the mid-point, making sure that the tape measure is snug but not tight.



If MUAC is <23.5 cm, BMI is likely to be <20 kg/m².
If MUAC is >32.0 cm, BMI is likely to be >30 kg/m².

The use of MUAC provides a general indication of BMI and is not designed to generate an actual score for use with 'MUST'. For further information on use of MUAC please refer to *The 'MUST' Explanatory Booklet.*

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Appendix 5 "Get your 10 a Day, The Nursing Care Standards for Patient Food in Hospital"

Please Visit:
https://www.health-ni.gov.uk/publications/get-your-10-day

The 10 nursing care standards for provision of patient food in hospital



All patients admitted to hospital are screened for risk of malnutrition.



Following screening by nurses, patients who are identified as malnourished or at risk of malnutrition are referred for and receive a nutritional assessment appropriate to their level of need.



Patients who require nutritional intervention will have a nursing care plan devised, implemented, evaluated and renewed to reflect the patient's nutritional and physical care needs and which documents both the dietetic plan and the nursing care assessment.



Patients who require food and/or fluid intake to be monitored will have that activity carried out in a way that is informative, accurate and up-to-date.



Patients who require support with eating and drinking are clearly identified.



Patients who require support with eating and drinking receive assistance when it is required.



Patients will be served their food and allowed to eat their meals without disruption.



Patients receive their meals in a physical environment that is conducive to enjoying their food.



Patients are offered a replacement meal if they miss their meal for whatever reason and can access snacks at ward level.



The patient receives food presented in a way that is appealing and appetising.

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Appendix 6

10 key characteristics of 'good nutrition and hydration care'

1. Screen all patients and service-users to identify malnourishment or risk of malnourishment and ensure actions are progressed and monitored.
2. Together with each patient or service user, create a personal care/support plan enabling them to have choice and control over their own nutritional care and fluid needs.
3. Care providers should include specific guidance on food and beverage services and other nutritional & hydration care in their service delivery and accountability arrangements.
4. People using care services are involved in the planning and monitoring arrangements for food service and drinks provision.
5. Food and drinks should be provided alone or with assistance in an environment conducive to patients being able to consume their food (Protected Mealtimes).
6. All health care professionals and volunteers receive regular raining to ensure they have the skills, qualifications and competencies needed to meet the nutritional and fluid requirements of people using their services.
7. Facilities and services providing nutrition and hydration are designed to be flexible and centred on the needs of the people using them, 24 hours a day, every day.
8. All care providers to have a nutrition and hydration policy centred on the needs of users, and is performance managed in line with local governance, national standards and regulatory frameworks.
9. Food, drinks and other nutritional care are delivered safely.
10. Care providers should take a multi-disciplinary approach to nutrition and hydrational care, valuing the contribution of all staff, people using the service, carers and volunteers working in partnership.

Appendix 7

Recording Oral Nutritional Supplements and action on Discharge

- BHSCT has agreed via the Drug and Therapy Group Dec 2018 that nutritional and thickened borderline products will be prescribed on the medical drug kardex.

- On Discharge from the ward these borderline products are to be entered onto the discharge letter.

- A 3-7 day supply of these borderline nutritional and thickened products will be provided for the patient from the ward supply.

Appendix 8

International Dysphagia Diet Standardisation Initiative

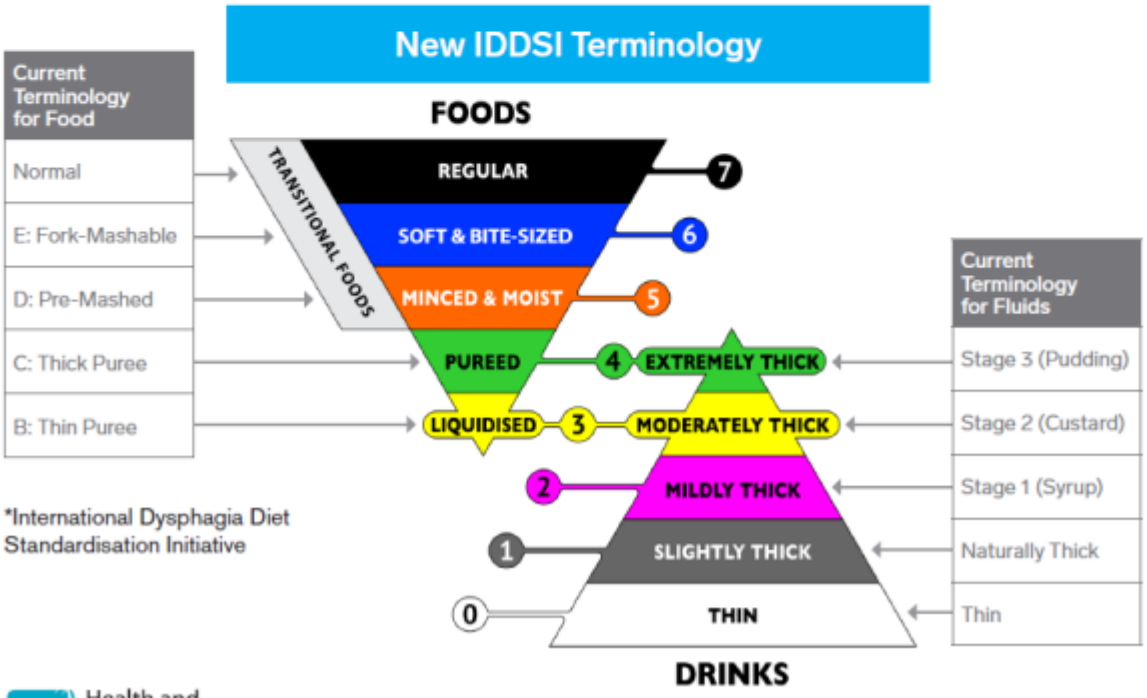
Terminology is changing for Modified Diets and Fluids for people with swallowing difficulties

UK National Descriptors ⟶ IDDSI*

Over the next few months watch out for:

- ✔ New terms and levels for thickened fluids and modified foods
- ✔ New dosage instructions for thickening powders
- ✔ New scoop sizes for some thickening powders
- ✔ New product labelling

For further information download the IDDSI app or see www.iddsi.org



Developed by BHSCT's Adult Learning Disability Good Information Group



Top 10 Standards for promoting Total Communication and creating Communication friendly Environments.

INCLUDE EVERYONE

Belfast Health and Social Care Trust

Giving Voice

photosymbols

Good Information Group

TOTAL COMMUNICATION



"Most adults with a learning disability have communication difficulties. Speech and language therapy can help to give a voice to people with a Learning disability by promoting a Total Communication approach. Which simply means communicating in the best way that someone can understand. Total communication includes everyone and ensures that all forms of verbal and non-verbal communication are recognised, valued and actively promoted.

Total Communication is about using easier words, keeping sentences short, showing what we mean as we speak or write; using objects, photos, pictures, symbols, sign and giving people enough time to understand and respond."

HSC Belfast Health and Social Care Trust

Giving Voice | Speech and Language Therapy transforms lives

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INCLUDE EVERYONE

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Communication Passports



Everyone communicates in a different way. If you have communication difficulties it is a good idea to have information about your communication available to anyone you communicate with. A Communication Passport can help to tell people what you understand and how you tell people things.

- They are positive, attractive, informative and good fun
- They can help you have a voice, make choices and get what you want
- They are essential for people who cannot easily speak for themselves.

You can keep the passport with you all the time so you can share it with the people you meet.

Hospital Passports

Hospital Passports help you get better support when you are in hospital.

They contain information about you to help staff care for you. They tell staff about your health, how you communicate, how you show pain, and what medication you are on.



What's Happening?



It is important to all of us to know what we are doing and when.

Everyone has the right to be told about things that are happening around them.

Some people need consistent routines with touch or objects to understand what is happening.

Other people rely on pictures, photographs or written timetables.

It is important that different ways of communicating are used all the time by everyone.

All people need a personal timetable or diary that they can understand so they know what will be happening during the day.

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MAHI - STM - 101 - 011015

Person Centred Planning



Person Centred Planning is a way of planning for life. It should





- You can choose who helps you to make the plan and how it looks
- Information in your plan can be recorded in words, symbols, pictures, photograp a digital recording
- It is owned by you. It's about your li t just the support you need
- Your plan will be updated when you want to make a change or have achieved a goal. This is called a review.

Personal Place Mat



A Personal Place Mat is a place mat you can make about your mealtime. It has all the important information about your mealtimes that other people need to know to help make your mealtime safe, successful and pleasurable.

It might tell people about the type of food you eat, how you choose your food, if you need any help to eat and if there are any risks.

Many people need some help and support at mealtimes. Having this information on a place mat allows staff to read it when they need to.

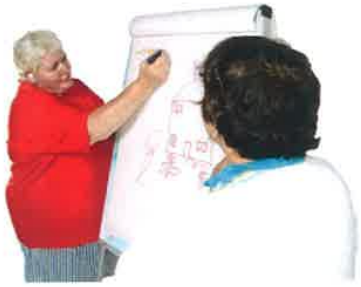
If you cannot easily speak for yourself, your place mat can help to keep you safe.

If you go to a new place to eat or there is a new person helping you they can read your place mat.

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Communication Training



Communication training helps to make sure that:

- Total Communication is central to services
- Everyone knows different ways of communicating
- Everyone knows about different tools that make communication easier like 'Objects of Reference'
- Communication tools are used all the time
- Everyone knows what Total Communication is. Services have a way of checking how good they are at communicating
- Everyone is supported in Total Communication
- Everyone is supported to make communication frienc environments.

Easy Information



People need information about lots of things from day-to-day. Some people need lots of help and support to read and understand information.

Making information easy read is about more than making your text big and adding a picture.

It is important to work with the people your information is for. Finding out together how you can make it easy to understand.

The creation of good accessible easy information is a skill which requires training and time.

All services should have an identified member of staff who works with their service users to create easy information.

To create good quality easy read information you need
- Knowledge of the standards
- Design training and symbol/picture software training.

Belfast Trust have a Good Information Group to help bring together people who are interested in creating easy read information. They offer training and help create and share resources.

Belfast Health and Social Care Trust
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Good Information Group

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Photographic Menu



Food is a big part of our day. It is a good idea to have photographs, signs and symbols on your menu. This will help people read what is on the menu and support them to make a choice by pointing.

It is easier to make choices when they are presented visually.

Looking at two pictures is much easier than thinking about the choice in your mind.

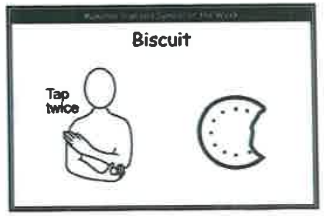
It can be a person's job to:

- Find out what is on the menu
- Select the photograph
- Take them round the building so that everyone can have a think about what they want to eat, and
- Display the menu in the dining room.

It can be a good idea to use photographs and symbols on cooking recipes and shopping lists.

A photographic menu can support people to design and plan menus.

Makaton





Total communication is about communicating in different ways. All forms of communication should be recognised, valued and actively promoted. One way is to use your hands to gesture or sign. Can you imagine if you couldn't understand speech? You would probably start to gesture and draw.

Makaton is a language programme using signs and symbols. Makaton is used with speech to help people communicate and can help develop language and literacy skills.

Makaton can help people who have difficulties with:

- Hearing
- Attention
- Understanding what people say
- Using speech to say what they want to say.

Makaton should be used in all environments to support communication. A good idea is to have a Makaton sign and symbol of the week displayed in your Service. This helps to tell everyone that your Service values other ways to communicate. It also helps to teach people a Makaton sign and symbol.

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Giving Voice
photosymbols
Good Information Group

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Clear Visual Signage



Having pictures, photographs or symbols as well as words on signs help more people understand the signs.

If you find it hard to read, having a picture with the word can help you.

All Services should think about the signs in their buildings and make sure all the signs can be understood by everyone.

It can be a good idea to use a photograph of people who use the room.

If you have pictures with your signs, more people will be able to find their way around your building on their own.

This will mean they will be more independent and will not need other people to show them the way.

You can even make some signs easy to understand by having something to touch, smell, hear and see. For example, all bottle with a smell along with a button to play the music introduce an Aromatherapy Room.

Resources



A communication friendly environment needs good quality communication resources.

Resources need to be kept where people can use them. It is important that people know where they are, know how to use them and can use them any time.

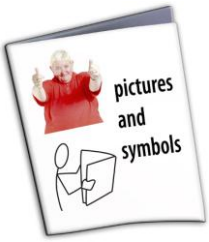
People need access to equipment to help make resources for example digital camera, printer, computer, laminator, symbol software, photograph software.

Some people may require alternative and augmentative communication (AAC) to augment or replace usual communication methods. There are low and high-tech AAC resources to support people to communicate. Low-tech AAC resources include communication books, picture boards and symbol choice boards. Examples of high-tech AAC resources include 'Talking Photograph Albums', 'Big Mack's', 'Tech Talk' and 'Listen to Me' devices.

Remember it does not have to be expensive!

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BHSCT Good Information Group
Top 10 Standards for Total Communication and Communication friendly Environments

Total Communication is about using easier words, keeping sentences short, showing what we mean as we speak or write; using objects, photos, pictures, symbols, sign and giving people enough time to understand and respond. In order to build shared communication with another person.

A communication friendly environment will have lots of communication methods available, because everyone is different!



Standard 1
If you have communication needs, will have a Communication Passport.



Standard 2
Information about what is happening, who is helping you and where you are going is presented in a way that you understand e.g. accessible timetables, who is working, choice boards, job rota, shopping lists, agendas, letters.



Standard 3
You will be helped to make your person centred plan using objects, videos, photos, pictures, symbols and writing.



Standard 4
If you have eating, drinking or swallowing difficulties you will have a personal placemat.



Standard 5
Your staff will have training so that they can use lots of different ways of communicating. For example Makaton signs and symbols, communication training, objects of reference, intensive interaction.



Standard 6
Your service will have an accessible menu (using pictures, photos, symbols, signs and easy words).



Standard 7
Your service will promote the use of Makaton by displaying a 'Sign and symbol of the Week'.



Standard 8
Your service will have clear accessible signage Names of people and places will be supported with photographs.



Standard 9
Your service will have at least one staff member who knows how to access and create good easy information resources. They will have training on how to make written information easy and will follow accessible writing guidelines. They will have training on how to create resources using symbols and photos. They will attend the Good Information Group and share good practice.



Standard 10
Your service will have access to resources to make easy information. Examples, paper, computer, colour printer, ink, laminator, digital camera, video camera, CD/DVD rewriter, Photosymbols, Communicate in Print2, Change Picture Bank, internet access.

- Northern Ireland Regional Adult Learning Disability Service Strategy (Adapted from RCSLT Position Paper 2010)

- A Regional Speech, Language & Communication Strategy for Adult Learning Disability Services March 2013



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Northern Ireland Regional Adult Learning Disability Service Strategy

1) Introduction

The political and social climate for Speech and Language Therapists (SLTs) working with People with Learning Disabilities continues to change and develop at pace. Over recent years SLTs have seen a development of posts and clinical specialisms, the development of a progressive Adult Learning Disability (ALD) national network with contribution from Northern Ireland and innovative practice both on a regional and national level. Ten years ago Speech and Language Therapy work within learning disability services would have been described as having a low profile but SLTs are increasingly recognised as a core profession within learning disability services.

Whilst there has been significant change and development within SLT Learning disability services in Northern Ireland, with evidence of progressive strategic thinking, there continues to be a degree of inequity in staff resources and service provision within the region and also in comparison to the national picture.

Within Northern Ireland SLTs are recognising that as well as **direct (face to face) interventions** there is a requirement that much of their work with adults with learning disabilities should be characterised by:

- **Partnership working –**with internal & external agencies
- **Developing a capable workforce** – via training & mentoring
- **Ensuring responsive communication environments and information that is accessible to the needs of People with learning disabilities**

This should be achieved whilst embracing the **Social Model of Disability**. Hence these themes will be referred to repeatedly throughout the paper and the communication strategy.

The SLT profession needs to ensure there is greater awareness of communication as a basic human right and this should be recognised at a strategic level by commissioners. It is therefore fundamental that people with learning disabilities themselves alongside SLTs lead the work and campaign for communication rights.

With this in mind, the Royal College of Speech and Language Therapists (RCSLT) commissioned the Steering group of the ALD National Clinical Leads Network to update the Position Paper for this clinical area. Following its completion in 2010 the position paper has been used by all 5 Health and Social Care Trusts in Northern Ireland to inform and develop SLT services.

It was agreed regionally that in order to reflect and promote best practice, a more formal regional communication strategy should be devised which encapsulates the fundamental themes in the RCSLT Position Paper (2010) and the key government policy drivers within Northern Ireland (Valuing People 2005, Good Practice in Consent 2003, Safe Guarding Vulnerable Adults 2007, GAIN 2010, Transforming Your Care 2012).

2) Purpose and Intention of the Document

The purpose and Intention of the following document is to influence and inform the following groups on the role and core business of SLTs working in this clinical area:

- SLT Senior Managers
- Learning Disability Service Managers
- Commissioners,
- SLT Education Providers
- Associated Organisations/Agencies in Northern Ireland

The document comprises two parts:

- A review of the key role / core business of SLTs in adult learning disability services in Northern Ireland, with suggestions for service provision/development, based on best practice (outlined in RCSLT Position Paper 2010)
- A regional speech, language and communication strategy - A tool to be used to influence and drive forward the communication needs of people with learning disabilities in Northern Ireland

The document has been written in such a manner that both parts can be used collectively or the communication strategy can be an independent tool.

3) Process for consensus

The process to gain consensus on the content of this document involved ensuring representation from all 5 Health and Social Care Trusts within Northern Ireland.

4) Definitions& Prevalence

Communication Difficulty

Up to 90% of People with Learning Disabilities have communication difficulties and it is acknowledged that barriers to successful communication are social ones e.g. a focus on written information/ questionnaires. People with Learning Disabilities may have difficulties in some or all of the following areas:

- Understanding speech, writing and symbols and interpreting environmental sounds
- Having a sufficient vocabulary to express a range of needs, ideas or emotions
- Being able to construct a sentence
- Maintaining focus and concentration in order to communicate
- Dysfluency e.g. stammering
- Being able to articulate clearly which may be due to related physical factors
- Social skills, a lack of which may prevent positive interactions with people (Kelly 2002)

Prevalence:

50-90 % of LD population have communication difficulties (Enderby and Davies 1989, RCSLT CQ3, 2006)

80% of people with severe LD do not acquire effective communication (RCSLT CQ3, 2006)

89% of People with Learning disability need SLT (Bradshaw 2007)

45 % of PWLD have serious communication problems (Bradshaw 2007)

Eating and Drinking Difficulties/ dysphagia

In 2004 the National Patient Safety Agency (NPSA) identified dysphagia as one of the 5 key areas of risk for people with Learning Disabilities.

Dysphagia refers to difficulty in eating, drinking or swallowing. It can lead to malnutrition, dehydration, reduced quality of life and choking. Asphyxia and respiratory related mortality are known to be disproportionately high in people with learning disabilities.

Prevalence:

There are no reliable prevalence figures for eating/ drinking difficulties in People with learning disabilities regionally or nationally.

Existing figures range from 36% based on general SLT caseloads to 73% based on inpatient populations (Leslie, Crawford and Wilkinson 2008) what is accepted is that People with a learning disability have a higher incidence of health problems including Dysphagia than the general population. (RSCLT CQ3, 2006, Death by Indifference 2007, Valuing People Now 2009)

For instance people with a learning disability are:

- 58 times more likely to die prematurely
- Three times more likely to die of respiratory disease
- 20 times more likely to have epilepsy
- Four times more likely to die a preventable death
- 65% more likely to be obese
- Almost twice as likely to be admitted to hospital in any one year
- Likely to have 2.5 times more health problems than other members of the population
- Significantly more likely to suffer physical disability such as hearing and visual impairment and chronic conditions such as obesity and CHD.

(Emerson and Baines 2010)

6) Learning Disability Service Model

The **Social Model of Disability** proposes that barriers, prejudices and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society. It recognises that while some people have physical, intellectual or psychological differences from a statistical mean, which may sometimes be impairments, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are " Normal" (BILD 2006)

It is therefore widely acknowledged and accepted both regionally and nationally that SLTS working within Learning Disability, work to a social model of care as per our fellow learning disability professions/service providers. This is not typically the model used in other SLT services.

7) The Role of SLT in Learning Disability Services

For those people with communication impairments, Speech and Language Therapists (SLTs) bring a unique expertise in assessing and making sense of the level of understanding, use of signs, expressions, verbal communication and interactions of People with Learning Disabilities. This expertise has the primary aim of helping both the person and in particular, those around them, to develop the most meaningful communication so that their experience needs and wants are better understood. Additionally SLTs brings specialist skills in managing eating, drinking and swallowing problems.

The Overall aim for SLTs is to work in this context (social model) by:

- **Enabling others to address barriers to communication that adults with Learning Disability experience**
- **Maximising the opportunities for positive interactions, relationships, participation and choice for People with Learning Disabilities**
- **Work in partnership with the individual and a variety of others to ensure that adults with Learning Disability can eat and drink as safely and enjoyably as possible. This in turn lessens the impact of the disability, promotes mental and physical health, which subsequently reduces risk/vulnerability**

Whilst Speech and Language Therapy interventions may be direct with the person, this often has limited effectiveness because communication is a function of a relationship, not simply a skill. More frequently, intervention is offered to support speech, language and communication in specific relationships; with families, carers, other health care professionals. Such work may include close collaboration to help assess and work to improve the psychological wellbeing, understand and help challenging behaviour and people with complex physical needs, which in turn may help reduce risk and/ or prevent costly admissions to learning disability & acute hospitals.

It is because of the needs of the Learning Disability population and the expertise of the SLT in speech, language, communication and dysphagia that they have key roles in reducing risk, developing relationships and building capacity and capability.

8) Tiered Model of Health and Social Care

The following model was used as a guide throughout the RCSLT Position Paper (2010) and is now accepted as a core framework for service delivery for Speech and Language Therapy services in Northern Ireland. This conceptual model suggests that by focusing on non - direct interventions at the lower tiers (1, 2, and 3) there should be reduced referrals and requirements for expensive intensive input at the highest tier (4).

It should be noted that SLT service delivery has historically focused predominantly at Tier 4- specialist interventions specific to the individual. Recent development of SLT learning disability services now recognise the need to target more than the individual and that in order to meet the communication and eating drinking needs of the individual SLTs need to interface with the general population, family/ carers and community services (Social Model of Care). SLT interventions at Tier 1, 2 & 3 will involve non-direct advice/ SLT input but it should form a substantial part of SLT core duties.

Currently in Northern Ireland limited but increasing SLT resource is directed to these tiers but there is a recognition that input into tier 1,2, & 3 will have a positive impact and reduce the amount of time consuming, costly and specialist (face to face) interventions required at tier 4 by:

- **Ensuring appropriate & timely referrals**
- **Ensuring appropriate & timely interventions**
- **Improving partnership working, thus achieving better outcomes**
- **Ensuring responsive communication environments, subsequently reducing communication barriers**
- **Reducing expensive intensive specialist interventions**
- **Preventing costly hospital admissions (Learning Disability & Acute)**
- **Reducing Risk**

It should be noted that although SLTs in Northern Ireland are increasingly required to input into Tiers 1, 2, & 3 and it is in keeping with best practice, it is only work at Tier 4 (face to face interventions) that is currently funded and recognised as core SLT

business by some commissioners and senior service managers. Unless this is addressed there will be a barrier to implementing any regional communication strategy for Learning Disability services.

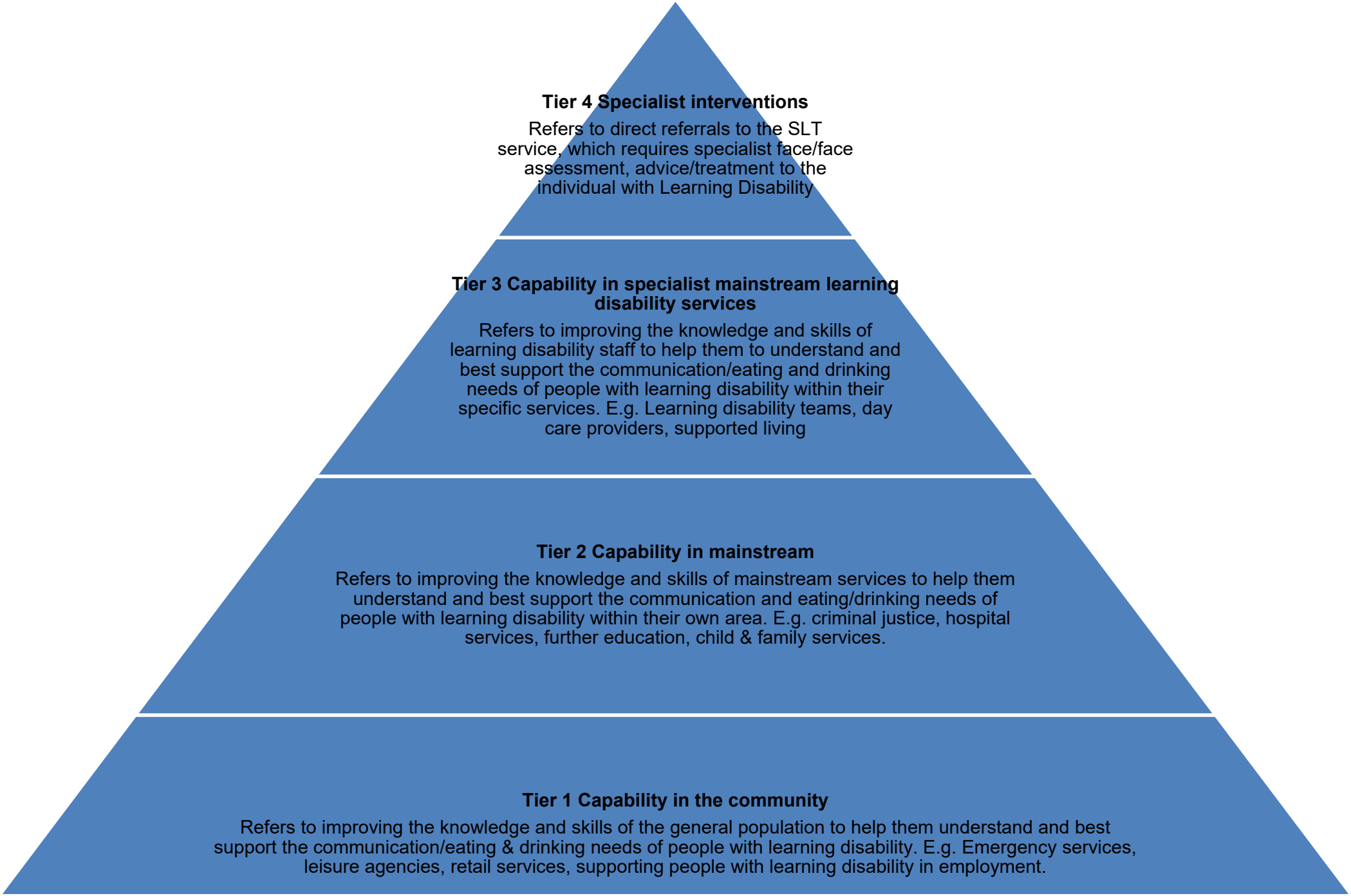

Tier 4 Specialist interventions
Refers to direct referrals to the SLT service, which requires specialist face/face assessment, advice/treatment to the individual with Learning Disability
Tier 3 Capability in specialist mainstream learning disability services
Refers to improving the knowledge and skills of learning disability staff to help them to understand and best support the communication/eating and drinking needs of people with learning disability within their specific services. E.g. Learning disability teams, day care providers, supported living
Tier 2 Capability in mainstream
Refers to improving the knowledge and skills of mainstream services to help them understand and best support the communication and eating/drinking needs of people with learning disability within their own area. E.g. criminal justice, hospital services, further education, child & family services.
Tier 1 Capability in the community
Refers to improving the knowledge and skills of the general population to help them understand and best support the communication/eating & drinking needs of people with learning disability. E.g. Emergency services, leisure agencies, retail services, supporting people with learning disability in employment.

Table1: Role of the Speech & Language Therapist in Northern Ireland within the Tiered Model

	Role of SLT
Tier 4	• Specialist assessment and evaluation which is specific to the individual service user's communication/eating &drinking. Including capacity assessment work • Specialist interventions specific to the service user e.g. alternative means of communication. • Specialist training regarding care plans. • Creating a responsive communication environment which meets the needs of the learning disability service user. • Specific advice/consultation and co-working with others (MDT, support staff, families, carers etc.) • Communicating information which may be contentious or complex in a manner which is appropriate to those involved e.g. eating and drinking advice, vulnerable adult & police interviews. • Devising service user specific resources.
Tier 3	• Non-direct advice and support. • Inform educate and influence the Learning Disability work force and carers/family on the communication/eating drinking needs of people with learning disability. • Training e.g. Inclusive/Total communication, adapting the communication environment, formal Makaton training, making information accessible, talking mats, dysphagia awareness training. • Development of service wide communication and dysphagia strategies and standards. • Facilitate Learning Disabilities services to meet RQIA standards.
Tier 2	• Inform, educate and influence mainstream services on the communication/eating and drinking needs of People with Learning Disability. • Support mainstream SLT services when managing people with Learning Disabilities e.g. stroke services, dental, podiatry, audiology • Communication/Dysphagia Awareness training for nurses/medics/AHP's. • Bespoke Makaton Training • Signage within specific environments e.g. A & E. • Supporting the development of accessible leaflets/resources e.g. attending the dentist. • Participating in and influencing strategy groups/forums e.g. Palliative care, dementia interface between acute and community settings.
Tier 1	• Inform, educate and influence the general population /community providers on the communication/eating and drinking needs of people with learning disabilities. • General training – basic communication training, Makaton taster sessions, role of the SLT, accessible information. • Support organizations in the development of accessible resources e.g. visiting the library. • Signage in community locations e.g. leisure centres, cafes, shops, • Promoting service user involvements.

Regional Speech, Language & Communication Strategy for Adult Learning Disability Services

What is a communication Strategy?

A communication strategy:

- Aims to improve communication for everybody with a learning disability so that they can exercise rights, make choices and have increased control of their lives.
- Should be able to be applied across services and within various life situations.
- Provides a structured and agreed plan to support and improve people's communication
- Should be a multi-agency plan which will aim to ensure that communication is embedded in all levels of service structure

Why is a Communication Strategy Required?

As an estimated 50-90 % of the Learning Disability Population have some degree of communication impairment (Enderby and Davies 1989, RCSLT CQ3, 2006). The long term effects of this impairment need to be taken into consideration throughout the person with a learning disability life span. Therefore there needs to be a greater awareness and acceptance by services and the community that communication is a basic human right. If this does not happen it is likely to have highly detrimental effects on the individual's health and social wellbeing, at an ultimate cost to health and social care.

In order for a communication strategy to be successful, it is essential that it involves the key elements of management support, training and networks, and to be underpinned by agreed and adequate resources (Money et al, 1997).

What is in the Communication strategy?

- **Section 1: Training**

This section outlines the importance of providing an agreed training programme to a wide range of others. It includes those who we believe should receive training as well as the type of training that Speech & Language Therapy (SLT) can offer. This is an essential element of developing and sustaining a capable workforce within health and social care, as well as within the wider community.

- **Section 2: Accessible Information**

This section outlines the need for information to be as easily accessible and as easy to understand as possible for those with learning disability. It includes details of what we can do to support others in the provision of accessible information.

- **Section 3: Working in Partnership**

This section discusses the importance of SLT working in partnership with a range of internal and external agencies and the wider community to help to reduce communication barriers and to support the ability of the learning disabled population to effectively access learning disability services and services within mainstream and wider community.

- **Section 4: Risks / Outcomes**

This section details the positive outcomes of providing Speech and Language Therapy intervention and the potential risks associated with not providing such a service in relation to the 3 key themes outlined above.

Section 1: Training

Speech and Language Therapists have a key role in educating/training others who come into contact with people learning disabilities including the family, health, education, social care staff and those within the wider community. There is research evidence of the positive impact of speech and language therapists conducting training packages on the behaviour of others in promoting communication with people with learning disabilities (RSCLT 2009), which in turn reduces risk/vulnerability.

Training is a high priority but without support from management at all levels and commitment from those working with adults with a learning disability, it is less likely to be effective in creating necessary changes in attitudes and practice. For that reason, Speech and Language Therapists recommend that **ALL** staff working in learning disability services should access foundation training as part of induction in the following areas, ideally within the first 6 months of commencing post.

- **Introduction to communicating with people with learning disabilities**
- **Role of SLT**
- **Makaton taster sessions**
- **Accessible information and visual support**

Speech and Language Therapists and service managers may identify other training priorities on a local basis such as:

- **Communication and Dementia**
- **Communication and Autism**
- **Communication and Challenging Behaviour**
- **Total Communication**
- **Talking Mats**
- **Makaton (beginners and follow up)**
- **Training in specific interventions**

Options of Training Delivery

- Full day (including closure days)
- Half day
- Short workshops (e.g. 1 hour+)
- E-Learning
- In house / central training venue
- Mentoring
- Individual / group
- Uni/Multidisciplinary (trainers/participants)

Frequency of Training

- Induction
- On-going training programme

(Frequency should be agreed with Locality Managers and Training Unit)

Training should also be made available to external agencies and the wider community as requested.

Training Responsibility

(1) It is the responsibility of the Speech and Language Therapist to identify training needs of the learning disability workforce, external agencies and the wider community as appropriate

(2) It is the responsibility of the Speech and Language Therapist to develop and provide training in line with current research and practice

(3) It is the responsibility of Direct Line Managers to identify staff training needs and incorporate these into their workforce development plan; release staff for training; and commit to implementation

(4) It is the responsibility of Senior Managers to agree to and promote the training strategy

Section 2: Accessible Information

Accessible information refers to making information easier for people to understand. Within the population of people with Learning disabilities approximately 90 % do not have recognised literacy skills. This means there is a high need to provide information in an accessible way. This may include for example, reducing the complexity of the language used or adding pictures or photographs. The Disability Discrimination Act (1995), states that it is a statutory requirement for organisations within Health and Social Services to make information accessible for people with learning disabilities.

Where possible accessible information should be tailored to the individual and therefore complement their communication skills and needs. The Speech and Language Therapist may have a role in:

- **Identifying an individual's communication strengths and needs including level of symbolic development, comprehension levels etc.**
- **Producing or commissioning specific accessible information for the individual and supporting its implementation.**
- **Advising key worker/s, other professionals and carers on how to produce and implement accessible information for an individual.**
- **Supporting the translation of relevant information into an appropriate format, e.g. care plans.**
- **Promoting responsive communication environments e.g. object cues, signage, timetables, menus etc.**
- **Promoting the use of person-centred strategies and resources. E.g. Individual specific programmes**

It will of course not always be possible to produce one resource or set of resources that will meet the needs of the whole learning disability population. With this in mind it may be beneficial to have a Speech and Language Therapist or suitably qualified

person alongside a Service User who have a role in developing and quality assuring all accessible information at a Trust or ideally a regional level. This may include work to address the following areas:

- **Developing written guidelines/local strategies/ training about how to produce and implement accessible information.**
- **Reinforce the legal context of accessible information and the responsibility of accessible information. This may involve for example, supporting the consent process, advocacy and decision making**
- **At a strategic level, involvement in planning/promotion of the use of accessible information.**
- **Acting as a consultant to organisations producing accessible information is terms of appraisal of the information.**
- **Supporting staff in the development of accessible information**
- **Signposting others to relevant materials/internet sites.**

(RCSLT 2009)

Responsibility for providing accessible information

Accessible information is an issue for everyone, and not solely the role and responsibility of Speech and Language Therapists.

(1) It is the responsibility of the Speech and Language Therapist to educate and support staff in the development, use of accessible information and to ensure that information is at an appropriate level for the individual and is not solely tokenistic.

(2) It is the responsibility of Direct Line Manager's to identify the information needed and to liaise with the Speech and Language Therapist regarding its development

(3) It is the responsibility of Senior Managers' to promote the production and implementation of effective accessible information

Section 3: Working in Partnership with People with Learning Disabilities and those who support them to access services

People with learning disability require different interventions throughout their lifespan. Many of the issues faced by people with learning disability will be the same as those faced by the general population, but they may require more help and support to successfully navigate these issues. Points of transition are critical times e.g. leaving school, transition to adulthood and adult services, resettlement from long stay hospitals and key events such as the death of parent needs careful management (RCSLT, 2009)

Communication disability is cited in all key strategic drivers across the UK (Valuing People Now 2008, Equal Lives 2005, Same As You 2000, Fulfilling Promises 2001) as a reason why people with a learning disability can be socially excluded or marginalised from their own communities. Disability Equality and Human Rights Legislation has meant universal services must not be discriminatory in their practises. The main strategic drivers cite the key areas of 'having a life' as being:

- **Better Health**
- **Housing**
- **Work and Education**
- **Relationships and having a family**

It is recognised that approximately 26% of people with Learning disabilities are admitted each year to hospital compared to 16% of the general population. (BILD 2004) Recent projects such as GAIN (2010) and MENCAP "Getting it Right" (2010) have highlighted the inequalities and difficulties that People with learning disabilities may experience whilst accessing mainstream health care. There has also been a significant shift in day care provision in recent years with a move away from traditional building based care (i.e. Day Centres) to a more community integrated approach (e.g. drop in centres, supported employment, college). In addition resettlement from long

stay learning disability hospitals to a range of community providers has been a key factor influencing Learning Disability Services. Given this there is an increased interface between those with Learning disabilities, the wider community and service partners. In order for this model to be achievable it is essential that effective communication is identified as a key priority.

Working with a wide range of service partners to improve awareness and knowledge of ways to overcome and reduce the impact of communication difficulties is a core role of the Speech and Language Therapist. SLT aims to enable people with learning disabilities to access personalised services by assisting them to:

- **Understand and express the choices available to them E.g. Visual Communication systems**
- **Express their views E.g. Picture Exchange Communication Systems (PECS), Talking Mats, Voice Output Aids**
- **Access services as appropriate within the wider community- Communication Passports, Communication aids, Accessible information leaflets**
- **Be included and involved- Ensuring responsive communication environments through relevant training and use of Total Communication**
- **Maintain health and wellbeing - health passports, personal placemats, accessible information for health checks, dentist etc.**

The following are key priority service providers who Speech and Language Therapy may interface with although it should be noted that this list is not exhaustive:

Community Based Services	Health Care Services
- Police and emergency services - Transport agencies - Leisure industries - Retail industries - Restaurants and Cafes - Employment - Housing - Substance misuse services - Religious and faith organisations - Key local and national bodies, e.g. Mencap, BILD, ARC	- Audiology - A & E - Gastroenterology - G P Practices - Maternity services - Acute hospital services - Ophthalmology - Dental and oral hygiene staff - Mental health staff - Patient advice and liaison services - Mainstream AHPs including SLT's - Day care staff / residential staff - Multi-Disciplinary Team

Responsibility

(1) It is the responsibility of the Speech and Language Therapist to work in partnership with those who come into contact with people with learning disability. It is also the Speech and Language Therapist's responsibility to promote their role in partnership working and to provide individual or general support to the learning disabled population. This may include joint goal setting and joint working.

(2) It is the responsibility of Direct Line Manager's within Learning Disability Services to request support from the Speech and Language Therapist and to implement a system of monitoring staff co-operation, e.g., supervision, CPD, training and communication champions/ link person

(3) It is the responsibility of Senior Management in learning disability services to agree to the Speech, Language & Communication Strategy as a core element of Learning Disability Services and to promote the involvement of the Speech and Language Therapist in supporting people with learning disability in accessing internal and external services.

Section 4: Outcomes / Risks

At the core of Speech and Language Therapy Services are vulnerable people. The credibility and value of Speech and Language Therapy depends on its commitment to and ability to help people at the most vulnerable times in their lives.

The table below summarises the possible positive outcomes of providing a Speech and Language Therapy service and the potential risks associated if SLT intervention is not sought and effectively implemented to support person with learning disability's communication needs

	Outcomes	Risks
Training	• Increased positive regard for people with learning disabilities • Increased awareness and examples of 'Total Communication'. • Increased confidence in communicating with those with Learning Disability for communication partners. • Consistent, stable placements and staff team. • Ensuring positive communication environments and capable and responsive workforces. • Increased Positive experiences for people with Learning Disabilities. • Reduce risk.	• Increased stigma • Increase in Challenging Behaviour • Breakdown in placement • Low staff confidence and morale in working with people with learning disabilities. • Increased vulnerability • Poor practice

	Outcomes	Risks
Accessible Information	People with Learning Disabilities can: • Understand and express choices available to them. • Express their views. • Access services • Understand their environment • Maintain health and wellbeing • Experience increased participation in activities.	• Exclusion • Withdrawal • Failure to meet legal requirements • Increased anxiety/distress for people with learning disabilities during hospital admissions and medical appointments. • Low awareness of services available to them.

	Outcomes	Risks
Working in partnership	• Increased positive experiences by people with a learning disability in accessing everyday activities and places. E.g. leisure. • Feeling safe and valued in the community • successful employment opportunities • Reduced healthcare inequalities • Improved health and life expectancy • Prevention of unnecessary hospital admissions • Staff will have appropriate skills to meet the communication needs of each individual • Increased compliance with professional guidance • Appropriate and timely referrals • Successful engagement with services • Improved uptake of mainstream/community services • Increased opportunities for meaningful social interaction • Increased involvement in decision making • Improved quality of care provided • Improved access to the safeguards and protections in criminal justice system	• Services fail to meet national/regional quality standards. • Placement breakdown e.g. employment/re-settlement. • Increased stigma • Increased abuse/hate crime • Increased vulnerability • Increased exclusion • Decline in Mental Health. • Distressing and unnecessary medical interventions • Diagnostic overshadowing. • Inappropriate use of physical interventions (e.g. physical restraint/splints). • Offending Over use of expensive specialist Learning disability services when mainstream services should provide adequate care

Conclusion

The key themes referred to throughout the communication strategy are priorities for Speech and Language Therapy work. These include:

- **Developing a capable workforce via appropriate and timely training**
- **Ensuring responsive communication environments and information that is accessible to the needs of People with Learning Disabilities**
- **Working in Partnership with people with Learning disabilities and those who support them**
- **Reducing risk/vulnerability**
- **Reducing costly interventions**

It is therefore essential that all those people and services with whom Speech and Language Therapy interface, work collaboratively to ensure that the communication needs of people with Learning disabilities are recognised as being integral to all facets of their life, subsequently breaking down barriers to social inclusion and increasing opportunities for participation.

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