NORTH & WEST BELFAST HEALTH & SOCIAL SERVICES TRUST

Development of a community based specialist assessment and treatment service for children and young people with a learning disability

STRATEGIC CONTEXT DOCUMENT EXECUTIVE SUMMARY

February 2004

Rev. of a
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Specialist
Assessment &
Treatment
Service for

- **Strategic Context Document for the Development of a Community Based Specialist Assessment and Treatment Service for Children and Young People with a Learning Disability**

EXECUTIVE SUMMARY

1.0 Background

1.1 Children and Young people with a Learning Disability are admitted to the Conicar Children's Service at Muckamore Abbey Hospital for specialist assessment and treatment services.

1.2 The Trust's agreed Business Case (2003) for the development of Muckamore Abbey Hospital indicates that, in line with the Regional Strategy and Boards' commissioning intentions, this service shall not continue to be provided in the hospital.

1.3 In its Children Matter Phase II proposals the Trust has included a bid for the reprovisioning of the Conicar Children's Service to a community location.

1.4 In November 2002 the Eastern Board's, Assistant Director of Social Services wrote to the Trust requesting that its 1995 Strategic Context document for the reprovisioning of the Conicar service, be reviewed and resubmitted.

2.0 Current Services

2.1 The Conicar children's service has 16 beds one of which is maintained for respite purposes. Children currently admitted to the service have a moderate/severe learning disability and complex needs including complex seizure disorders, autism, epilepsy, superimposed psychosis and challenging behaviours. The overall aim of the service is to re-integrate the children admitted back into community life.

2.2 Analysis of activity indicates that the unit tends to run at full or near full occupancy. Over the three year period 00/01 – 02/03, 31 children, (7 girls and 24 boys), had a total of 154 admissions to the Conicar children's service. Seven of the children were from the Northern Board area and twenty- one from the Eastern Board area with the other two coming from the Southern Board and the Republic of Ireland. The youngest child admitted was 6 years old and the oldest had just turned 18.

2.3 An Asset Condition Survey indicates that the physical condition of the Children's accommodation is generally poor with a requirement for major capital investment. It does not meet the accommodation requirements indicated by the guidance on **Standards for Children's Homes** (Ref DHSS&PS-1997), the **Welfare of Children in Hospital** (DOH,1991) and **Getting the Right Start; National Service Framework for Children – Standard for Hospital Services** (DOH 2003).

3.0 Strategic Background

3.1 The statutory framework for the provision of services to children in N. Ireland is established in the **Children (Northern Ireland) Order 1995**. This puts a duty on statutory bodies to care for children with disability and provide services aimed at minimising the effect of disability.

3.2 The **Regional Strategy for Health & Social Well-being for 1997-2002** set a specific target that the number of children with a learning disability admitted to specialist hospitals should, other than in exceptional cases, reduce to zero by 2002.

3.3 The EHSSB **Commissioning Statement for Specialist Treatment Services for Children with a Learning Disability and Complex Needs** (June 1998) indicates that services for children presently offered through Muckamore Abbey Hospital must cease by 2002 in order to meet Departmental targets. The Commissioning Statement sets out a number of proposed and complementary developments including the provision of a small community based residential assessment and treatment service for children primarily with severe challenging behaviour.

3.4 The NHSSB **Service Specification: Specialist Children's Unit for Children with a Learning Disability & Severely Challenging Behaviour** (February 2000) indicates the Board's intention to continue to commission access to specialist acute provision for a small number of children.

3.5 The SHSSB has informally indicated that it would wish to consider commissioning access to a regional assessment and treatment service in support of its local services for children and young people with a learning disability.

4.0 Establishing the Strategic Direction

4.1 **The National Service Framework for Children, CAMHS Working Group – Learning Disability Working Paper** (2003) indicates that separate inpatient provision for those with significant learning disabilities will normally be required due to a number of factors including their increased vulnerability and their requirement for a compatible peer group.

4.2 To respond to the strategic direction outlined the Conicar Children's Service should be reprovided to a community location. The reprovided service should be developed within an overall service framework consistent with the four tier model of Child and Adolescent Mental Health Services (**ref. Together We Stand 1995**) and must reflect good child care practice.

4.3 In completing the revised Strategic Context Document the Project Team identified the following attributes of this service:

Who

Children and young people aged under 18 with a Moderate/Severe Learning Disability who present with severe and complex challenging behaviours with a variety of aetiologies.

Aim

The overall aim of the service shall be to treat and discharge the child back to their home and school.

Registration

Consideration should be given to dual registration for the Unit. It would require to be registered as a health facility in order to meet current Mental Health legislation where a child requires to be detained for treatment.

Services

The following elements of an effective service were identified;

- Clear and efficient agreed protocols for referrals and/or care pathways.
- Child centred model providing for the needs of the child as a whole.

- Working in partnership with and providing support to parents.
- Outreach/Inreach working. Careful development of a collaborative approach and close liaison with local education, local health and social services as well as families.
- Admission. Timely referrals from secondary services, multi-disciplinary pre admissions panel, planned admissions and appropriate emergency admissions.
- Assessment and Treatment. The provision of an integrated, high quality, holistic, multi- disciplinary assessment and treatment service based on the needs of the individual child and their parents.
- Time limited duration of admission. Objectives for each admission should be clearly understood and agreed at the outset.
- An age appropriate physical environment. The unit should provide a child appropriate setting in an accessible community location.
- Outcomes. The objectives for each admission will be individually negotiated and agreed for each child.
- Discharge. Multi-disciplinary and multi-agency discharge planning should start at the time of admission and form part of the admission contract with parents and community staff .

4.4 Scale of Service Required

To meet Commissioner requirements an eight bedded unit should be provided. This would facilitate separation between younger and older children into two adjoining 4 bedded units and provide a sufficiently viable scale of service within which to develop and maintain the levels of specialism necessary.

4.5 Conicar Reprovision - Non Core Services

The current Conicar children's service also provides specialist respite and shared care services. In order to facilitate the closure of Conicar all these current needs must be planned for and addressed by the provision of alternative services in the community. Under Children's Matter phases I and II the Eastern and Northern Boards have brought forward proposals for a range of community based residential and specialist respite services which properly targeted should address the 'non- core' services currently provided in Conicar.

5.0 The Way Forward

5.1 The Strategic Context requires the formal support of the three Commissioning Health and Social Services Boards prior to formal submission by the Trust to the Department for approval.

Upon approval of the Strategic Context an outline Business case will be completed to help identify the optimal service development and capital investment required in order to deliver the agreed vision of service as outlined in the Strategic Direction section of the document. Upon approval of the Outline Business Case a Full Business Case including private finance options if applicable and capital development programme shall be completed.

5.2 Affordability: The current cost of the Conicar Children's Service is £920,000. This is similar to an estimated community cost included in the Eastern Health and Social Services Board's Commissioning Statement on a per bed basis. The Conicar costs contain apportionments of overhead and shared costs at the hospital which would be difficult to extract. It is therefore unrealistic to expect that the full cost of a reprovided service would be funded through the marginal cost savings of closing the current service.

6.0 Outline Business Case

6.1 The Trust would now wish to proceed, with Commissioning Board support, to the completion of an Outline Business Case for the development of a Community Based Specialist Assessment and Treatment Service for Children and Young People with a Learning Disability.

An objective of the Trust's Outline Business case would be to consider a range of options including possible partnership arrangements in both the provision of care and the provision of accommodation. This would include consideration of Private Finance Initiative solutions.

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Audit of Learning Disability in Northern Ireland
S/988803

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Overview

This audit of research in learning disabilities was commissioned by the Department of Health, Social Services and Public Safety (DHSSPS) as part of the independent review into Mental Health and Learning Disability. The project had four inter-related strands.

1. ***Creation of a Directory of Research Studies into Learning Disabilities undertaken in Northern Ireland.***

The Directory is prepared in Microsoft Access and is available free-of-charge on a CD-Rom from Room 12J10, School of Nursing, University of Ulster, Newtownabbey, N. Ireland BT37 0 QB . The Directory contains details of over 300 studies which are searchable by key-words, topics and authors. Each study is rated regarding the sample used and the research design employed.

2. ***A strategic review of learning disability and service provision in Northern Ireland.***

The main aim of this strand was to synthesize current international thinking in relation to the concept of learning disability; to identify the main influences on the development of modern, cost-beneficial services that will reduce existing inequalities and improve the quality of lives of people with this disability and of their family carers. Issues relating to staffing of services were also to be reviewed.

3. ***Reports on six specific topics***

The Learning Disability Committee had set up six Task Groups to prepare reports on topics of particular significance to the Review. These were: accommodation and support, day opportunities, children and families, physical health, mental health and ageing issues. .The third strand of work involved a review of literature in these six areas drawing primarily on Northern Irish studies but also incorporating the insights from international research that would inform best practice in modern services.

4. ***Organisational arrangements in support of people with a learning disability.***

The fourth strand included a review of current organisational arrangements for learning disability services in these islands with particular emphasis on an analysis of the strategies used to promote greater partnership working among agencies, sectors and departments. This strand also involved a survey of over 30 respondents of their experiences of inter-agency working and suggestions for improvements.

Project Steering Group

The work of the project team was overseen by a Steering Group chaired by Siobhan Bogues (Chair of the Learning Disability Committee for the NI Review). The members were: Lorna Masterson (UCHT); Pascal McKeown (Mencap) and Paul Roberts (Positive Futures).

Critical reviewer

Dr Oliver Russell acted as a critical reviewer of initial draft reports. A psychiatrist and formerly Director of the Norah Fry Research Centre, University of Bristol, he has been a senior policy adviser to the English Department of Health on Learning

Disabilities. He is chair of Trustees for British Institute of Learning Disabilities and of the Learning Disability Advisory Committee for the National Assembly of Wales.

Format of the report

The final report is presented as a series of self-contained chapters with references and appendices relating to each chapter listed at the end.

Each chapter begins with an overview and is subdivided into a number of sections. Throughout the chapters the main conclusions are highlighted in boxed form. The overviews and the boxed conclusions provide a quick summary of the contents of the report.

Acknowledgements

Our thanks to the project steering group from their wise counsel, Dr Oliver Russell for his insightful suggestions and Damien O'Neill and Suzanne Abbot for their assistance with information gathering.

Disclaimer

All the views and opinions in this document are those of the authors and should not be taken as representing those of the Department of Health, Social Services and Public Safety or of the Project Steering group.

Chapter 1:

A Strategic Review of Learning Disability and Service Provision in Northern Ireland

The main aim of this chapter is to synthesis current thinking in relation to the concept of learning disability and the main influences on developing modern, cost-beneficial services that will reduce existing inequalities and improve the quality of lives of people with a learning disability and of their family carers.

The chapter is divided into six sections.

Section 1 reviews modern thinking about disability and covers values, legislation, terminology and definitions.

Section 2 focuses on definitions of learning disability and implications for assessment.

Section 3 examines the numbers of people with a learning disability in Northern Ireland.

Section 4 describes the impact of the troubles on this population.

Section 5 outlines current service provision and funding sources.

Section 6 summarises issues of inequalities for people with a learning disability

This chapter is supplemented by a series of Appendices that contain further elaboration of key issues.

Appendix 1.1: Legislation in Northern Ireland
Appendix 1.2: Terms used internationally for learning disability.
Appendix 1.3: International definitions of learning disability.

Section 1: Modern thinking about disability

During the 20th century a radical change occurred in societal perceptions of people with disabilities. Old conceptions that emphasised their differences and deficits have been replaced by the idea that they are people first and foremost. Likewise, beliefs about helplessness, worthlessness and exclusion have been superseded with aspirations for their 'full participation and equality' within society and efforts made to reduce their disabilities through provision of appropriate supports, treatments and education.

Rights statements

To a large degree this revolution stemmed from the advocacy of disabled persons, their parents and professionals. A major plank of their campaigning was based around human rights and in 1971 the United Nations issued a landmark Declaration on the Rights of Mentally Retarded Persons. Article 2 states:

> *"The mentally retarded person has the right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential".*

A later Declaration on the Rights of Disabled Persons (1975) asserted that

> *"Disabled persons whatever the origin, nature or seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and as full as possible".*

Later the UN Standards Rules on the Equalization of Opportunities for Persons with Disabilities (1994) spelt out in detail the actions member states needed to take to make this a reality. In particular, it was noted that:

> *"Persons 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" (Para 26).*

This thinking is reflected in recent EU Directives and UK legislation and policy-making. For example, Article 26 of the Charter of Fundamental Rights of the European Union (Nice, 2000) states that:

> *"The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community."*

Likewise, Section 75 of the Northern Ireland Act (1998) states:

> *'A public authority shall, in carrying out its functions to Northern Ireland, have due regard to the need to promote equality of opportunity .... between persons with a disability and persons without"*

This Act also set up Equality Commission in Northern Ireland and in 1999, a Disability Rights Commission was established Great Britain. Both bodies have the following duties:

> (a) *To work towards the elimination of discrimination against disabled persons;*
>
> (b) *To promote the equalisation of opportunities for disabled persons;*
>
> (c) *To take such steps as it considers appropriate with a view to encouraging good practice in the treatment of disabled persons; and*

(d) To keep under review the working of the Disability Discrimination Act 1995.

Legislation

In tandem with these broad statements of principles, the legal entitlements of people with a learning disability have been delineated in a series of Acts and Orders. These are briefly summarised in Appendix 1.1. To a large degree they mirror legislation enacted in Great Britain and they are reflective of legislation in other European countries and North America.

In addition, the Disability Discrimination Act (1995) in the UK makes it unlawful for service providers and employers to discriminate against people with disabilities and places a duty on them to make 'reasonable adjustments' for disabled people and also necessary adjustments to their premises so as to overcome physical barriers to access. The Act will be fully implemented in October 2004. It has potential to make a major impact upon the provision of services to people with disabilities. Appendix 1.2 gives fuller details about the DDA along with examples of recent case law which is the primary way by which the full provisions will be tested in practice.

Recent legislation largely serves two main purposes.

- First, it ensures that people with disabilities have access to the same range of opportunities as their age peers and that they are not discriminated against.
- Second, it should provide people with disabilities with the additional services and supports they require to assist them to achieve a better quality of life and social inclusion.

These twin goals also reflect the aspirations of most people with disabilities; their family, carers and professional advocates.

Hence at the start of 21st century there is remarkable agreement across all constituencies on social policies concerning people with disabilities in general.

Future Legislation

Even so, a number of deficits in Northern Irish legislation in particular should be noted.

- The Special Educational Needs Discrimination Act (2003) has not been extended to Northern Ireland as yet although a draft of the Order is now available for consultation and should be introduced in 2005.
- The Scottish Executive has introduced The Adults with Incapacity (Scotland) Act which has been well received. There is no comparable Act covering Northern Ireland.
- The existing Mental Health (NI) Order (1986) can be construed to infringe the rights of persons with 'mental impairment' to sexual relationships.
- There is no legal entitlement to services post-school; to individual person-centred planning or advocacy as is the case in other jurisdictions.

Policy changes

Changes in societal perceptions of disability are also reflected in the policy aspirations that underpin much of current services planning and delivery, although with the proviso that aspirational statements are not always translated into practice.

These changes are clearly seen in the recent reviews of learning disability services undertaken in these islands over the past 15 years.

In the Republic of Ireland, the 1990 review of services provided for persons with a mental handicap stated:

> *The philosophy underlying our approach was the right of every person with an intellectual disability to as fulfilling and normal a life as possible….. We believe that with the right kind of services the overwhelming majority of people can live in the community. (p.iii).*

The 1995 Review of Policy for people with a Learning Disability in Northern Ireland that superseded earlier policy guidance, DHSS (1978) "Services for the Mentally Handicapped in Northern Ireland: Policy and Objectives".) stated that

> *The aim of Government policy for people with a learning disability should be inclusion ... which stresses citizenship, inclusion in society, inclusion in decision-making, participation so far as is practicable in mainstream education, employment and leisure, integration in living accommodation and the use of services and facilities, not least in the field of health and personal social services.*

The Scottish Review published in 2000, identified seven principles that underpinned all their considerations and recommendations. These were:

- *People with learning disabilities should be valued. They should be asked and encouraged to contribute to the community they live in. They should not be picked on or treated differently from others.*
- *People with learning disabilities are individual people.*
- *People with learning disabilities should be asked about the services they need and be involved in making choices about what they want.*
- *People with learning disabilities should be helped and supported to do everything they are able to.*
- *People with learning disabilities should be able to use the same local services as everyone else, wherever possible.*
- *People with learning disabilities should benefit from specialist social, health and educational services.*
- *People with learning disabilities should have services which take account of their age, abilities and other needs.*

The National Assembly of Wales (June 2001) set out the principles underpinning their framework for services for people with a learning disability in Wales:

- People with a learning disability are full citizens equal in status and value to other citizens of the same age
- They have an equal right to expect a high quality of life - in practice this means having exactly the same expectations of decent health, education, housing, safety and financial security, protection from harm, positive social relations and roles within family and community, employment opportunities, personal development, emotional well-being and civic rights.
- They have a right to decide for themselves and to join in all decision-making which affects their lives, with support if necessary.

- They have access to the support of their families and the communities, of which they are a part, and to general and specialist public services to improve their chosen quality of life.

Finally the English Review (2001) identified four key principles at the heart of the Government's proposals in *Valuing People* : They were:

> ***"Legal and Civil Rights:*** *People with learning disabilities have the right to a decent education, to grow up to vote, to marry and have a family, and to express their opinions, with help and support to do so where necessary.*
>
> ***Independence:*** *Promoting independence is a key aim for the Government's modernisation agenda. ... While people's individual needs will differ, the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this.*
>
> ***Choice:*** *Like other people, people with learning disabilities want a real say in where they live, what work they should do and who looks after them. But for too many people with learning disabilities, these are currently unattainable goals. We believe that everyone should be able to make choices.*
>
> ***Inclusion:*** *Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community.*

Policy statements from Health and Social Service Boards

In the recent past all four Health and Social Service Boards in Northern Ireland have issued policy statements to guide their commissioning of services. The Eastern Board (1996) for example state that the overall objective of services for people with a learning disability is:

> *"To work with individuals to help them achieve and maintain a valued lifestyle"*

Similarly the Northern Board (1998) listed its two objectives as being:

> *"To enable people with elanring disabilities to live lives as normal as possible, maximising opportunities for personal development and fulfillment; and*
>
> *To secure and develop a coordinated and balanced range of generic and specialised services in keeping with those needs".*

These aims are echoed in the Western Board's Social Care Review (2000).

> *"The theme of inclusion is now a driving force within policy development for people with a learning disability. Coupled with this is a clear emphasis on moving from a service (which at one time was) largely based on long term institutional care to one which is community orientated and largely community based".*

One of the service principles listed by the Southern Health and Social Services Board (2000) is:

> *"Services should be developed to ensure they respond flexibly and sensitively to the needs of individuals and their carers and should provide the opportunity to choose from a range of options."*

Conclusions

In summary then, there is a striking similarity about the values that should imbue service provision as reflected in national and local policy statements. The main themes centre around:

- Inclusion within mainstream society as a right and the use of mainstream community services.
- Support to individuals that will reduce the impact of the disabilities on their lives.
- Focus on individuals needs and aspirations and hence the provision of choices
- Empowerment of people with learning disability to make decisions
- Partnerships are required to make these values a reality.

Section 2: Defining and assessing learning disability

Terminology

These new conceptions are to some extent realised in the changing terminology used to describe this condition. Derogatory terminology of old Acts such as 'Mental Deficiency' (with its references to idiots, imbeciles and the feeble-minded) and 'Mental Subnormality' has given way to terms that more accurately reflect the essential features of this condition.

However there is no universal agreement on suitable alternatives with the term 'learning disability' being unique to Britain and Ireland. Appendix 1.2 reviews the different terms in use internationally.

The dilemma of finding a suitable name has no solution. Basically the problem lies not in the dearth of names (as there are any amount) but in finding one term to define a grouping of people who have many diverse characteristics, so a single label will never be adequate.

Rather what is needed is a range of labels to do justice to the diversity of people who are presently grouped together as 'having a learning disability'. Thus people should be defined within different dimensions according to their characteristics and needs. We shall return to this point after we examine definitions of disability. To date, the new thinking has had relatively little impact on the way this disability is defined.

Models of disability

Much professional practice and service delivery assumes that a disability is a characteristic of the person and hence people can be categorised into those who are 'disabled' and those who are not. This has been labelled the 'medical model' of disability or more accurately the 'person-centred' model of disability. Here disability is viewed as being susceptible to objective assessment and diagnosis and to possible treatment; the aim of which is to adjust the person so that he/she better fits into society. Allied to this are notions of constancy (the prospect of real change is limited); dependency (the person needs to be 'looked after') and passivity (the person with the disability is incapable of self-determination). This is the model around which many specialist disability services have been built.

In this model of disability the focus has been on defining and categorising a person's impairments or limitations in functioning with little or no attention paid to the social, cultural and physical environments in which people live and which can constrain their lifestyle and levels of functioning.

Disabled activists in particular have been to the fore in criticising this model of disability.

- Most definitions stem from a medical emphasis and do not reflect issues of importance to people with disabilities, such as education, employment and housing;
- Terminology is used that is devaluing and stigmatising of persons with disabilities; and
- They focus on people's deficits with little attention to their talents and competences.

Appendix 1.3 documents the significant definitions of learning disabilities presently in use internationally. It quickly becomes apparent from a cursory reading that the older definitions – and those mostly used in Northern Ireland – emphasise the personal deficits approach to disability.

Social model of disability

An alternative model of disability that is gaining greater credence has been termed the 'social model of disability'. Promoted initially by disabled people themselves, this model views disability as the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers he/she may face. In short, people are disabled by the society in which they live. The World Health Organisation has reviewed the literature on societal influences on disability (www.who/int/icidh).

In the social model, the key assessment is in terms of the type and extent of the accommodation or intervention required to the environments so that the person functions as well as other people in their society. Obvious examples are the provision of lifts instead of stairs and access to hearing aids. Both of these accommodations will reduce the disabilities experienced by either wheelchair users or hearing impaired persons.

This model of disability better reflects the emphasis in Government policy on social inclusion; encapsulated in slogans such as 'full participation' and 'equality of opportunity'. The focus of interest in both assessment and treatment of disabilities is then placed on the barriers that prevent people with disabilities to participate fully in society and the supports and adaptations that would enable this to happen. Disabled activists have focussed especially on access to education, employment, community facilities, transport and housing as these are primary determinants of social inclusion in most societies.

As Appendix 1.3 describes, more recent definitions of learning disability do take more account of social influences although these are frequently added as supplementary to the core definition that remains firmly centred on a person's deficits.

The implications of adopting a social model of disability have been most fully developed by the World Health Organisation in their recently introduced International Classification of Functioning, Disability and Health (abbreviated to ICF) (2001). This radically different approach uses a framework to encompass all aspects of human health and health-relevant components of well-being. It is applicable to all people, not just those with disabilities (Bickenbach et al, 1999).

A person's functioning is conceived as a dynamic interaction between health conditions and contextual factors both personal and environmental. ICF does not classify people into discrete groups but rather aims to describe the situation of each person within an array of health-related domains (including bodily impairments and illnesses) and in the context of environmental and personal factors that are known to influence their levels of functioning with society. Each person is given an array of codes – usually between 3 and 18 to describe their particular characteristics.

It is unclear how this information could be summated to define groups of people although it should be possible to do so, with the understanding that the same person can equally appear in different groupings. These groupings are unlikely to be mutually exclusive.

Common Features

Although these two models of disability start from very different perspectives they do converge around four basic dimensions in describing the disabilities experienced by the person. These are summarised in the following Box.

Box: Four dimensions for describing disabilities

1. **Impairments** – the presence and absence of specific impairments are noted including illnesses, mental and emotional problems;
2. **Functional limitations** – especially in the areas of activities of daily living (including personal care);
3. **Social inclusion** – the extent to which the person has access to education, transport, employment, housing, recreation etc; and
4. **The supports** (physical and human) available to the person and those that are lacking but needed. These can link with the previous three dimensions, for example certain professionals may address the person's impairments whereas others focus on functional limitations.

Hence a person needs to be assessed on all four dimensions in order to obtain a more complete picture of them; their life-style and needs. Equally four different terms (or more) should be used to locate the person within subgroups such as: "a person with Down Syndrome who has a severe hearing impairment, with significantly low scores on a test of intellectual disability and who requires assistance with all personal care needs; living in a residential home with 30 other residents".

Defining Learning Disability

International definitions of 'learning disability' include three elements all of which must be present:

- Significant impairment of intelligence that includes an increased impairment to understand new or complex information, and to learn new skills.
- Deficits in social functioning or adaptive behaviour and a reduced ability to cope independently.
- The disability started before adulthood (usually before 18 years of age) and has a lasting effect on development.

However the precise terminology used in definitions varies (see Appendix 1.3 for fuller details).

Northern Ireland Definitions

In Northern Ireland there has been relative consistency in the definitions used although the terminology is not always consistent. For example, mental handicap is defined in the Mental Health (NI) Order 1986 as:

"A state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning."

This definition or minor variants is also used in Social Security (Disability Living Allowance) Regulations 1991; Police and Criminal Evidence (NI) Order, 1989; Registered Homes Act 1984 and Regulations; Road Traffic Act, 1988[1].

However this definition omits a key feature included in all international definitions, namely that the disability or impairment is present from childhood. Moreover the term 'development of mind' is impossible to define accurately; a point to which we shall return. (Foundation of People with Learning Disabilities, 2001).

The Mental Health (NI) Order also defines to two further categories:

> *Severe Mental Handicap*: 'A state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning'; and
>
> *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'.

This is in contrast to the Mental Health Act (1983) for England and Wales which defines two categories in relation to learning disability, namely 'mental impairment' and 'severe mental impairment'. As Bankhead (2004) noted, this means there are significant differences in the two jurisdictions on which treatment and guardianship orders can be made. In Northern Ireland there needs to be severe (rather than significant) impairments of intelligence and social functioning *and* 'abnormally aggressive or seriously irresponsible conduct'. He concluded that "*despite the adoption in many instances of apparently similar definitions, there are sufficient differences between the jurisdictions to lead to significant differences in the ways in which the (mental health) laws are operated*"(p. 3).

Assessing for a learning disability

There are significant problems in operationalising these definitions so that people can be reliably and validly classified as 'learning disabled.'

Much reliance is placed on scores of intelligence tests. Learning disability is conventionally defined by scores that are two standard deviations below the mean, that is of 70 and less (mild learning disabilities) with more severe disabilities having scores less than three standard deviations, i.e. 55 or less. However given measurement errors, scores should be expressed as a range. These often fall within 5 points either side of the obtained score. Moreover a person's score is likely to vary to some extent across different tests and over time. It is particularly difficult to assess accurately scores less than 50 hence there it is impossible to operationalise distinctions between moderate, severe and profound as older definitions tried to do (Foundation of People with Learning Disabilities, 2001). Individual assessments by a person trained in psychometric testing and using tests of known reliability and validity with appropriate norms are considered essential.

Learning disability cannot be assessed solely in terms of intellectual functioning; there must also be significant impairments in adaptive functioning. This is frequently overlooked. However the available instruments for measuring this are not as sophisticated as intelligence tests nor do they provide a normative base for comparisons. The British Psychological Society (2001) recommend that "*despite the*

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[1] This information is taken from British Psychological Society (2001) *Learning Disability: Definitions and contexts.*

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" (p. 7).

Finally it needs to be established especially when assessing adult persons, that the disability started during the developmental period and before 18 years of age.

The American Association of Mental Retardation (2002) proposed five dimensions on which a person required to be assessed taking into account the wealth of knowledge that has been generated in recent years as to critical features of this condition.

I Intellectual abilities

II Adaptive behaviour – divided into conceptual, social and practical skills.

III Participation, interactions and social roles

IV Health – physical health, mental health and aetiological factors

V Context – environmental and cultural.

In addition on each dimension, the appropriate levels of support required by the individual are categorised: intermittent, limited, extensive and pervasive.

Implementation

The full extent to which these formal assessment procedures are currently used within existing services is not known. It is likely that they are used by educational psychologists as part of the statutory assessment procedure for special educational needs. However they are less likely to be used in reviewing statements or during the transition from school.

Clinical psychologists are likely to make use of them when people are referred for a psychological assessment related to the possible presence of a learning disability. But given the small numbers of such professionals within Northern Irish services, the proportion of people with recent formal assessments is likely to be small.

It is much more likely that other professionals, such as community medical officers and consultant psychiatrists, classify many more persons as learning disabled but they do so largely on the basis of clinical judgement and less formal assessments (Bankhead, 2004).

Indeed it is questionable whether the time and effort involved in undertaking thorough assessments to determine whether or not a person has a learning disability could be justified. This raises the crucial issue as to the purpose of assessments, especially those that aim to determine whether a person has a learning disability.

Why assess?

Assessment of learning disability can serve three main purposes. Often these are not distinguished both in the rationale for the assessment and in terms of the methods used.

Service eligibility: The goal of this assessment is to limit scarce resources to those that require them. This can be wide ranging – for example is a person eligible to receive services under the learning disability programme of care from Health and Social Service Trusts - or more specific entitlements to receive Disability Living Allowance; or to require treatment from a speech and language therapist. In these instances it is important that common assessment tools and definitions are used to be fair to everyone. They need to be reliable but not overly detailed so that they can be administered to all applicants to the service.

Legal Protection: In this instance the assessment has a more specific function in order to determine if the person is entitled to the protection and/or entitlements afforded under specific legislation. Here the focus is often on whether or not the person meets the defined criteria. This test is easier to apply with more precise criteria. Only a small number of decisions are legally challenged but when it happens, the assessments used will be critically examined in great deal.

Assessment of needs: These assessments are more individually focussed and they attempt to specify the particular forms of support the person and/or their carers require. In these instances different assessment tools and methods may be used by different professionals making the assessment according to the person's needs.

(NB. Other reasons for undertaking assessments can be to obtain a profile of the population of people with a learning disability to assist in the planning of services - another form of assessment of needs- or to make comparisons within and across countries in the number of people identified as having a learning disability. These usually rely on broad' criteria and simple rating-type scales.)

Redefining eligibiity

Given the multi-dimensional approach to defining learning disability noted earlier, eligibility to services in particular needs to be reconceptualised.

It is worth remembering that similar issues of service eligibility arise for everyone in society. However these are usually defined in broad, easily verifiable means such as a person's age entitles them to a free pass for public transport or their place of abode determines their eligibility for GP services.

Thus the first lesson is that people with a learning disability do not need to be specially assessed to determine their eligibility for services that are available to the mainstream population as long as they meet the same criteria as their fellow citizens. Thus if there were no specialised services for people with a learning disability, as is now the case in various Scandinavian countries, many issues surrounding definitions disappear.

Second, in order to determine a person's needs for specific services that arise from their learning disability, the essential requirement is to specify the need rather than the disability per se. For example, two people with a 'learning disability' can have very different needs in terms of assistance required with their personal care. Indeed people with very different impairments – physical disabilities, brain injury and chronic mental illness - may then have common needs for specific assistance. Hence the focus of assessment should be on the functional limitations arising from the impairment and/or social inclusion and supports required. Assessment tools for this are not well developed at present.

Third, the onus is on the service to precisely define the criteria that makes a person eligible for the special service. In many ways we still live with the old idea of one learning disability service – i.e. eligibility of admission to the programme of care substituting for the institution - rather than recognising the diversity of services that are delivered within a learning disability programme of care. Hence each defined service within the overall programme of care needs to produce the criteria for admission, especially for those services where demand exceeds supply, such as the provision of respite (short-term) breaks; attendance at day centres. This recognises the reality that everyone with a learning disability does not require every service. The assessment of the person then becomes one of whether or not they meet the criteria for entitlement. Again it is likely that these assessments will be based around functional limitations, social inclusion and supports. This approach also recognises that people's need for a service can be for on a short-term as well as a long-term basis.

Fourth, thorough and precise assessments will be required when there is a high likelihood of legal challenges; most likely when people's rights and freedoms are being denied. Again the more precise the definitions used in law, the easier it will be to ascertain whether or not a person meets the criteria set; although it is equally recognised that Government may be reluctant to do this as it makes legislation very restrictive. Hence judges will undoubtedly continue to be involved in legal processes. Until such times as present laws change, it is likely that assessments of intelligence and adaptive functioning will be required to determine if a person has a 'mental impairment' as defined in legislation. However this requirement need not carry over into definitions regarding eligibility for service provision for the reasons noted earlier.

Conclusions

- Definitions of eligibility need to move away from assessing a person in terms of abstract conceptions about a lack of intelligence or poor adaptive behaviours towards those that specify functional criteria for service entitlement based mainly around assessments of an individual's needs. Assessment tools for doing this need to be developed.
- This is increasingly happening in services with the move towards person-centred planning but a similar transformation needs to occur at a higher level of service specifications.
- There must be a recognition that no one definition is adequate to cover all circumstances.

Section 3: The numbers of people with a learning disability in Northern Ireland

The DHSS&PS through the capitation formula review group, commissioned a study of the administrative prevalence of learning disability based on data contained in various existing information systems such as Child Health System and Soscare (McConkey, Spollen and Jamison, 2003).

Previous studies, most recently by McDonald and Mackay (1996), had focussed on the Southern Health and Social Services Board. They reported variations in the prevalence rates (per 1,000) across the three Trust areas: namely Newry & Mourne 9.04; Armagh & Dungannon 6.72; Craigavon & Banbridge 5.85. Likewise in the Republic of Ireland, prevalence rates have consistently varied across Health Boards (Health Research Board, 2003).

Given these findings, it would be unwise to extrapolate from data gathered in particular localities to estimate the numbers in other Boards throughout Northern Ireland.

Using data from various databases, the numbers of people with a learning disability by age groupings and severity of disabilities were estimated as follows (data from the Republic of Ireland is provided as a comparison).

Age Bands	Moderate	Severe/Profound	Total	Overall Prevalence	*RoI Prevalence**
0-19	6432 39.3%	1718 10.5%	8150 49.8%	16.30	7.69
20-34	2504 15.3%	1047 6.4%	3551 21.7%	10.16	9.59
35-49	1489 9.1%	949 5.8%	2438 14.9%	7.04	7.81 *(35-54 yrs)*
50+	1473 9.0%	753 4.6%	2226 13.6%	4.54	3.62 *(55+ yrs)*
Totals	**11,898** **72.7%**	**4468** **27.3%**	**16,366** **100%**	**9.71**	**7.35**

* *Health Research Board (2003)*

This data suggests that more children in Northern Ireland are recorded as having a learning disability than in the Republic of Ireland. However in the latter, the figures are based on children in receipt of, or requiring special services. In Northern Ireland many of the children classed as having 'a learning disability' in the Child Health System may not be making any demands on special services. The prevalence figures for people aged 20 years and over are broadly comparable.

Similar data is not available for Great Britain although in Scotland an estimated 5.45 per 1,000 are in regular contact with services with others having occasional or short-term contact (Scottish Executive, 2000).

The decrease in numbers of people by age reflects the shorter life expectancy of this group in the past. However this is changing due to medical advances.

There appear to be few persons with a learning disability in Northern Ireland from ethnic minorities although it is likely that there are some from the travelling and Chinese communities. This data is not available from present data systems although under Section 75 of the Northern Ireland Act (1998) it should be recorded.

Finally, these numbers represent people known to services at a particular point in time. It is possible that the actual numbers are greater of people with a learning disability are higher and they may come close to the often quoted figure of 2% of the population having a learning disability.

Future predictions of population

All the indications are that there will be increased numbers of people with a learning disability in the future (Foundation for People with Learning Disabilities, 2001). This results from:

- Increases in maternal age for births.
- Increased survival rates of 'at risk' infants due to improved healthcare.
- Increased life expectancy of people with a learning disability including those with more complex needs.
- The 'bulge' of children with a learning disability born in the 1950s and 1960s is now working its way through into the 50 plus age group.
- A higher birth rate among ethnic minorities along with an associated higher rate of a learning disability in these populations could also result in increased numbers.

The major factor underlying upward pressure on the prevalence of learning disabilities is their increasing life expectancy (National Assembly for Wales, 2001). It is now thought that most adults with a learning disability in developed nations who live past their third decade are likely to survive into old age and experience the normal ageing process. Presently in England and Wales there are more adults with severe learning disabilities aged over 45 years than there are such children aged under 15 years.

There are some trends that may result in decreasing numbers:

- Increasing availability of prenatal screening congenital and other abnormalities leading to terminations.
- The advent of 'gene therapy ' to correct congential abnormalities.
- Improved health care and early intervention for 'at risk' infants leading to fewer becoming learning disabled.

Overall it is impossible to predict the impact of these opposing influences. Estimates from the Department of Health suggest that the trend towards an increasing number of people with a learning disability will be sustained over the first two decades of the Twenty-first Century. This is consistent with the 22% reported increase in the number of people on local authority registers for people with a learning disability in Wales between 1990 and 1999 (National Assembly for Wales, 2001).

In England, a presumed growth of 1% per year for the next 15 years was made of people with moderate to severe learning disabilities. This figure may need to be higher for Northern Ireland as we have had a higher birth rate until comparatively recently and limited availability to terminations of pregnancies.

Even so a 1% increase per annum in the present adult population of 8,200 would mean an adult population of 9,500 by 2019. A 1.5% increase per annum would result in 10,200 persons. It might also be that numbers would continue to rise for a further 15 years before deaths matched births.

However it is likely that higher proportions of these individuals would have increased support needs due to old age or additional complex needs and the impact on resources required to meet their needs would be in excess of a 15 -25% growth in services provision.

Finally there may be increasing numbers of persons from ethnic minorities if immigration increases in Northern Ireland as it has done in the Republic of Ireland.

Research in Great Britain has found tentative evidence to suggest higher prevalence rates of learning disabilities amongst some minority ethnic groups, for example, South Asian groups have higher incidences of children and young adults with severe learning disabilities. It is unclear whether these higher rates are biologically or genetically linked with ethnicity, or are the result of other factors that have an impact upon minority ethnic groups, such as socio-economic status, poverty, access to health care or classification practices; a point which we will develop later (Foundation for People with a learning disability, 2000).

Service settings

Nearly all those under 20 years of age known to services were living with family carer. However of the 7,970 persons aged 20 years and over, the distribution of people in the three types of service settings are shown in Figure 1.

Comparable figures for the Republic of Ireland (2001) are: Hospitals (4%); Residential services - 5 day and 7 day (39%); Community (57%). In Great Britain, an estimated 63% of adults live in private households and 37% in some form of residential accommodation. The numbers living in long-stay hospitals in GB are now less than 1% of the total population. (Kavanagh and Opit, 1999). This data suggests that over twice as many adult persons are in residential provision in Great Britain and in the Republic of Ireland than in Northern Ireland.

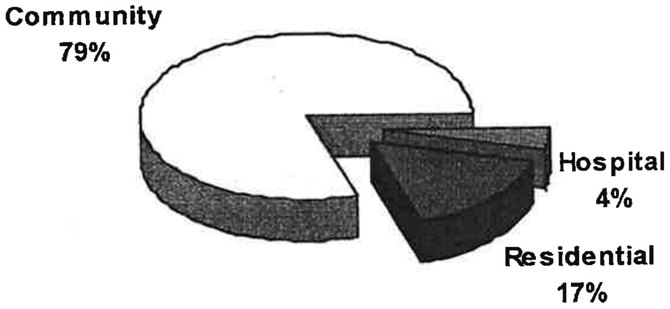

Figure 1a: The proportions of people aged 20 years and over living in different settings

Hospital: In 2003, an estimated 440-470 persons were living in hospitals and had no other address to which they could be discharged. Some were recent admissions because their previous placement had broken done but most had lived in hospital for many years with a mean length of stay of 20 years. They form the population that requires to be resettled. Their mean age is around 50 years and two-thirds are recorded as having 'severe' rather than 'moderate' learning disabilities.

Residential Settings: Around 1,900 persons are in some form of residential setting, most commonly registered residential care homes and nursing homes. However growing numbers of people are in supported living arrangements especially in the EHSSB area. Their mean age is around 48 years although this varies across the 11 community HSS trusts from 41 years to 55 years. Around two-thirds are rated as having 'moderate' learning disabilities and one-third as severe disabilities (the converse of the Hospital population.) Most have been in their present place of residence for an average of 7 to 8 years.

Family settings: This includes people living with family carers (66% of total); in their own accommodation (10%) or with a spouse/partner (3%). Around three-quarters of the children are aged 10-19 years and around 4 in 5 are rated as having moderate learning disabilities. Over half the adults are under 45 years of age and around 70% are considered to have moderate learning disabilities.

Of the people aged 14 years and over living with family carers, nearly one third presently live with a single carer and over 25% with carers aged over 65 years. Around one in six carers were rated as being in poor health (McConkey and colleagues, 2000, 2002, 2003a,2003b) . These are all risk factors that make present care arrangements vulnerable and may necessitate alternative accommodation having to be found for the person, sometimes with little or no notice. An estimated 1,600 persons were thought to require alternative care arrangements in the next 10 years.

Over half of the families (54%) are dependent on State benefits as their main source of income and a further 6% were rated as having an income of less than £12,000 per annum. Of the remaining 40%, only 6% were rated to have an income in excess of £24,000 (McConkey et al, op cit).

Links with social and economic deprivation

Internationally there is clear evidence for a link between higher prevalence rates of mild/moderate learning disabilities and poorer socio-economic status and unstable family backgrounds (Roeleveld et al, 1997). This link with severe learning disabilities is less clear-cut with some now questioning earlier findings of no association with socio-economic status (Louihala, 1995).

However families may be poorer for other reasons. It has been estimated that parents of disabled children earn around 25% less than parents of non-disabled children (Jarbrink and Knapp, 1999). In addition the direct costs to families of bringing up a child with severe disabilities is about three times greater than the cost of bringing up a non-disabled child (Dobson and Middleton, 1998).

Recent research in Northern Ireland has identified a significant association between the measures of deprivation and the prevalence of people with a learning disability recorded on service information systems irrespective of the severity of their disability (Dixon 2003). This is based on a small area analysis (quasi-electoral wards) of the characteristics of people living within each as ascertained by the national census or other form of surveys using representative sampling. In Northern Ireland the association is best captured by three indicators of deprivation, namely there tends to be more people with a learning disability in wards which have:

- Higher proportions of people aged 16 to 74 with no educational qualifications;
- Higher proportions of children in households with job seekers allowances.

- Higher proportion of adults with a limiting, long-term illness.

Consideration is currently being given to using these indicators as a means for allocating funding for the learning disability programme of care across Boards and trusts as is done for other health and social service programmes. This is intended to overcome 'supply effects' of funding in that funding is not given because services already exist but on the basis of likely need within local populations.

However the broader message is that many people and families are disadvantaged not only because of the disability but also because of social and economic deprivation.

Conclusions

- **Around 1 in 100 Northern Irish citizens are known to statutory agencies because of a learning disability.**
- **Northern Ireland may have a higher prevalence of learning disability than Great Britain but comparable with that of the Republic of Ireland.**
- **The numbers of adult persons with a learning disability may rise by up 25% by 2019. The proportion of people with more complex needs will also increase.**
- **Learning disability is linked with social and economic deprivation.**

Section 4: The impact of the 'troubles'

The recent history of Northern Ireland has been marked by a prolonged period of violent conflict known locally as the 'troubles'. Although the impacts were particularly marked in certain interface areas in urban areas; notably in Belfast and the City of Derry, and in the Border counties, all aspects of civic life in Northern Ireland have been affected.

Various research studies have been undertaken to study the impact of the troubles in general (Fay et al, 1999) and on children in particular (Smyth et al, 2004). In addition, studies have been undertaken on the impact on service provision, notably by Smyth et al (2001) on health and social service provision in North & West Belfast.

In all these reports, people with a learning disability do not feature. In part their invisibility may result from their small numbers but more likely it is because of the presumption that their 'special-ness' negates them from being influenced by the same factors that afflict their non-disabled peers.

Indeed this presumption may well explain why in the midst of a segregated educational system, the only schools attended by children from both communities over the past 20 years were mostly special schools. Likewise much of the service provision for adult persons is non-denominational although the balance of attenders from one rather than another 'community' can be determined by its geographical location. Murray and Heatherington (1998) caution that these service patterns may not reflect good anti-discriminatory practice but rather they are further evidence for the exclusion of people with a learning disability from the true tests of citizenship which tend to be based around political, cultural and religious beliefs.

Moreover in common with other public institutions in Northern Ireland, special schools and services seem to maintain a form of silence about issues of division, conflict and sectarianism (Smyth et al, 2001).

Troubles-related impacts

There is plenty of anecdotal evidence to suggest that the lives of people with a learning disability have been affected by the troubles and that this continues up to the present. For example, the Holy Cross School dispute in Belfast necessitated the occasional closure of an adjacent day centre for people with a learning disability and fuelled calls for its relocation from this interface area.

The findings from studies undertaken with other populations are also likely to resonant with the experiences of at least some people with a learning disability. Smyth et al (2004) summarise these in terms of impacts that are more frequently experienced and less visible to those that are less frequently experienced but highly visible. Starting with the former these include:

- The risk of straying into areas where they did not feel safe.
- Getting stopped and searched by security forces.
- Sectarian verbal abuse.
- Parents having to take extra security precautions to secure home or workplace.
- Knowing victims of punishment attacks

- Young people pressurised to engage in sectarian activities
- Involvement in paramilitary activity
- Member of family killed.

The clinical experience of professionals suggest that people with a learning disability were recruited by paramilitaries and that a number were subsequently convicted of serious offences.

More generally though family carers were reluctant for their family member with a learning disability to travel independently and opportunities for social, employment and educational activities across the community divides were severely restricted. There are indications from local research that this social isolation may be one of the most widespread and lasting legacy of the troubles (see chapter 3).

However it is impossible to generalise about the overall impact that the troubles have had on this client population as no systematic studies have been undertaken and even when these have been done for the wider population, the results are difficult to interpret given the presence of other confounding variables such as socio-economic deprivation and lack of contrast groups from outside Northern Ireland.

Possibly the more important lesson is for the future and to ensure that people with a learning disability and service staff are fully involved in all initiatives to promote greater understanding and respect for the two main cultural traditions in Northern Ireland.

Conclusions

- The impact of the troubles on people with a learning disability has been largely ignored.
- Nonetheless they too will have experienced in varying degrees disruption to their lives and restrictions to their movements.
- A test of their citizenship will be their full participation in efforts to promote greater understanding and respect between the different cultural traditions in Northern Ireland.

Section 5: Service provision and funding

There is no accurate record of all services provided under the learning disability programme of care either by a HSS Trust or by a subcontractor in the private or voluntary sector. Nor are there accurate records of the number of people availing of them although some figures are available as part of the Korner returns made by HSS trusts to the Department.

However it is very apparent that over the past 20 years in Northern Ireland there have been major changes in service provision and an expansion in the range of services on offer. In particular:

- The three hospitals for people with a learning disability have reduced considerably in size and are evolving from providing long term residential care towards the provision of short-stay assessment and treatment services.
- There has been a major growth in the provision of residential home, nursing home and day services for people with a learning disability by a range of independent (private, not-for-profit or voluntary) providers.
- The provision of education for children with a learning disability has become the responsibility of Education and Library Boards and increasing numbers attend Further Education Colleges.
- A network of community learning disability teams made up of personnel from different disciplines have developed providing services to people with a learning disability living alone, at home and in community residential facilities.
- There is a growing appreciation of the need to facilitate and provide increased access to mainstream health, social services and education for people with a learning disability.

The result is a diversity of services with a wide range of personnel employed in them. In addition to the Hospital and Residential services noted above, these can include the following:

Professional services: Social workers, care managers, community learning disability nurses, behaviour therapists, allied health professionals and therapy aides; psychologists and psychology assistants, and psychiatrists.

In addition people with a learning disability will receive services from GPs, community medical officers, health visitors, district nurses and other specialist practice nurses, dentists and oral hygienists, podiatrists, opticians and audiologists. They will also avail of Accident and Emergency services and be seen by a range of hospital consultants on in-patient or out-patient basis.

People can be admitted to specialist hospitals for assessment and treatment services. A small number of people may need to be accommodated in semi-secure accommodation because they present a danger to others and/or have committed a crime.

Day and evening opportunities: Day centres, vocational training, social firms (sheltered work), work experience, supported employment, befriending schemes, advocacy schemes, sports and recreation schemes, social clubs.

Family and home support: Domiciliary workers, home helps, provision of aids and appliances, home adaptations, fostering and adoption services; breaks with host families; long-term adult placement schemes; respite breaks away from their usual residence settings, information and advice services, counselling services.

Other services: Services are also provided through other statutory and non-statutory agencies, notably schooling and further education, disablement advisory service (career guidance), social security benefits and housing. Voluntary organisations also provide a range of support services for parents and carers along with social and educational events for people with disabilities.

This complex web of service provision creates its own particular difficulties.

- Family carers complain that they are not given information about all the services and help that is available. Indeed it is likely that no one person is fully aware of the full range of assistance that can be available to families (McConkey, 2003).
- Families may have to contend with various different specialists who may give conflicting advice. The concept of a 'named' or 'key worker' for the family is not well established (Sloper, 1999).
- There is likely duplication within and across services in terms of record keeping, assessments and staff roles. There are few or no co-ordinated service plan for individuals.
- The full range of services is not available in every locality and probably never will be. Often new services have been developed in an area at the instigation of particular individuals. However this can produce inequalities within and across Trust areas; a pattern that is evident in most countries (Bailey and Cooper, 1997).
- The need for 'joined-up' working across different government departments, statutory agencies and other service partners is very evident in the field of learning disabilities although it has received scant attention in Northern Ireland. We shall return to this in a later section.

Person-centred services

In recent years, increasing attention is being given to creating more person-centred approaches in service delivery.

In part this reflects the particular needs of this client population who often demonstrate wide variability despite having a common label such as Down Syndrome. Hence under the Code of Practice of Special Educational Needs, a Statement of Needs is drawn up for each individual student that details their particular educational needs and provides a plan for responding to them. Likewise Individual Care Plans or Therapeutic Plans are drawn up by other professions.

Another rationale for individual planning, such as happens with care management in social services, is to produce more cost-effective services in that packages of care can be better tailored to each individual.

Latterly Person-Centred Planning (PCP) has been promoted as producing more effective outcomes for people with a learning disability in new styles of community-based services (Department of Health, 2001). Moreover by placing the individual at the centre of the process, it is more respectful of their rights and autonomy as a service-consumer (O'Brien et al, 1997).

However the conclusions of a systematic review of 21 studies of person-centred planning found limited evidence for their efficacy (Rowe and Rudkin, 1999). Less than half the reports in the review described the outcomes for service-users although the qualitative data that was presented provided considerable evidence that this form of planning resulted in more person-centred plans than did professionally-lead individual programme plans. Also there was evidence of increased choices being offered to clients and desirable outcomes were achieved in the areas of social, educational and residential supports. However In the absence of suitable contrast groups, it was not possible to conclude that the planning process per se produced these outcomes.

Others have argued that the greater need is for person-centred actions and services rather than plans per se. Mansell and Beadle-Brown (2004) question the untested assumption that plans will translate into services. Rather they highlight the need for change in power relationships between staff and their 'clients'; changes in funding arrangements and improved staff training and supervision.

Conclusions

- Although people with a learning disability form a very small proportion of the total population, the nature of their disability is such that they require a wide range of supports that extend beyond the remit of health and social services.
- There is evidence that the person's family provides much of this care and support and to a greater extent than in Great Britain or the Republic of Ireland.
- A trend towards more person-centred services is evident.

Funding

The learning disability programme of care accounts for 7% of Health and Social Service Board Expenditure (£105.7 million at 31 March 2002). This equates to approximately £62.9 per person of the total population. (This figure has remained the same since 1997. In the previous year the figure had been 5.8%).

Comparable figures for England at 2001/02 rates were £3,335milion: £67.9 per person – 8% higher than in Northern Ireland.[2] The comparable figures for Wales was £69.5 (National Assembly of Wales, 2001) while in Scotland the comparable amount was £55 (Scottish Executive, 2001).

In the period 1996 to 2002 HPSS spending on the learning disability programme of care rose from £59 million to £105.7 million; an increase of 79%. The share of the total HPSS spend also rose from 5.8% to 7.0%.

The proportions of revenue monies spent in the DHSS&PS learning programme of care as at 31st March 2002 is shown in Figure 2.

Comparisons of Figures 1 and 2 indicates a substantial mismatch between the proportion of monies spent on hospital provision with the numbers of people in hospital settings (30% versus 4%). This can be explained to some extent in that the hospitals are funded to provide short-term assessment and treatment services for people in residential and family settings and that all the costs of specialist medical and psychiatric services, and possibly of other professionals, are costed to hospitals

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[2] *These figures are taken from a ministerial answer by Jacqui Smith (17 December 2002) given to a parliamentary Question for gross costs in England and from returns made by Trusts in NI on their spend in the learning disability programme as at 31 March 2002. In her answer the Minister also gave a commitment that in England "the overall level of funding for social services, including that for learning disability will increase, by on average, 6 per cent in real terms over the next three years."*

although they also serve people living in community settings. Even so, the costs of maintaining people in hospital are very much higher than other settings.

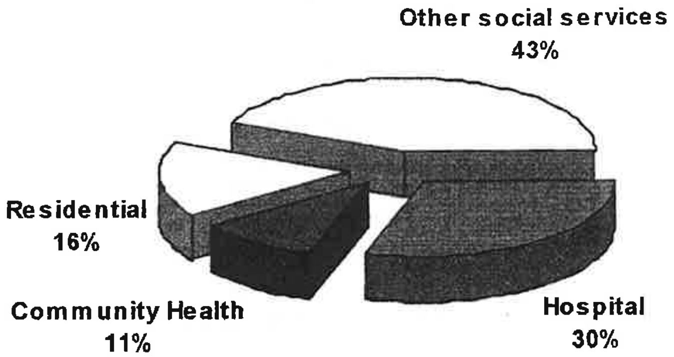

Figure 2: The proportions of monies spent in the Learning Disability Programme of Care – year end 31 March 2002 (Total £105.7 million).

Moreover in the period from 1996, the proportion of monies in the different sectors has been relatively constant. By contrast in England the proportion spent on long-stay hospitals fell dramatically as people have been resettled and by 2004 this will be close to zero. (However health funding will still be required for short-term assessment and treatment admissions; low-level and medium secure accommodation and for specialist long-term placements for people with complex needs.).

The largest areas of expenditure under community health are in Allied Health Professionals (£4.39 million: 40% community health budget) followed by nursing (£2.76 million: 25%).

In personal social services the largest item of expenditure is on day services (£24.5 million: 55% PSS funds) with £5.85 million spent on social work.

Other funding sources

It is difficult to obtain precise figures for the amount of monies expended by other Government departments on people with a learning disability[3]. This will include:

Department of Education: on statutory assessments and statementing; the provision of learning support in mainstream schools and special schools.

Department of Social Development: social security benefits such as Disabled Living Allowance and Mobility Allowances plus contributions to Supporting People and the capital costs of special needs housing.

Department of Employment and Learning: Further education; vocational training, disable advisory service – career guidance.

In addition various learning disability services have been subvented by European monies although it is anticipated that these will end in 2006 or soon after.

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[3] *The Needs and Resources Group set up as part of the NI Review may be able to provide this information in due course.*

Variation in costs

To date there has been relatively little research into the costs of learning disability services and in particular into the value-for-money offered by different service models.

Most research in Great Britain has focussed on different forms of residential care and found that costs vary dramatically within all forms of residential services. There can be a four-fold differences in costs of these services and similarly a three-fold differences has been reported for day services (Felce, 1996). A significant proportion of the variation is accounted for by the level of dependency of the residents. Once this is taken into account, there appears to be little association between the size of the home and costs. Larger is not necessarily more cost-effective.

Newer community-based services are generally more expensive than support provided in older style accommodation, although this largely results from avoiding the inadequacies of these services rather than inherent economies of scale in larger establishments (Foundation of People with Learning Disabilities, 2001).

A Northern Irish study into the costs of providing residential services for people relocated from a long-stay hospital (McConkey et al, 2002) found similar wide variation in costs as in Great Britain with the highest median costs being in registered residential care homes which cost £36,000 per annum (range £16,000 to £41,500) with costs generally lowest in registered nursing homes: median of £19,000 (range £11,000 to £36,000).

Another study into the costs of supported living (McConkey and McConaghie, 2001) reported a variation in weekly costs of £255 to £544. This was considerably less than figures cited for similar schemes in England (range £302-£1,311) although some of these employed waking night staff.

The largest element in costs is attributable to staffing which accounts for around 75% of revenue costs. There is some evidence that better staff:client ratios yield better outcomes for the service-users although others have argued that it is the way that staff carry-out their roles; particularly in offering active support (Jones et al.,2000) and the skill mix of staff that is more crucial.

Conclusions

- A wide range of services are now provided to support people with a learning disability and their carers both formal and informal.
- However in Northern Ireland more money is spent on hospital provision and consequently less in community services.
- We have as yet an incomplete understanding of the wide variation in the costs of providing services which are apparently similar and of how to achieve 'best value' in the services that are provided to this client group.

Section 6: Inequalities and people with a learning disability

Many people who have a learning disability do not start from a 'level playing field' in that their disability may hinder them in accessing services, or may lead others to discriminate against them. Therefore, special measures will be required for many people with a learning disability to ensure they are not treated inequitably.

This section of the review is in three parts, the first part summarises the evidence of inequalities this group experience in relation to topics that are subsequently covered in more detail in the following six chapters - accommodation needs, day opportunities, children and families, physical health, mental health and ageing.

The second part explores fundamental issues relating to human rights and discriminatory practice.

The third part examines differences between services in Northern Ireland and those elsewhere in Great Britain and the Republic of Ireland. In addition possible inequities across Northern Ireland are noted.

Potential inequalities

Reviews of the national and international literature have identified inequalities generally experienced by people with a learning disability. It is likely that these also apply in Northern Ireland and were evidence exists for this it is noted.

Family Carers

Families of learning disabled people are likely to be exposed to a range of inequalities. They may receive less informal support from family and friends, have less opportunities for leisure pursuits and breaks and have been found to experience more problems with poor housing (Twigg & Atkin, 1994).

Evidence suggests mothers face the most inequality within care giving families. Mothers are less likely to be in employment (Booth & Kelly, 1999) and they are more likely to report symptoms of ill-health such as depression (Andersson, 1993; Truesdale and McConkey, 2001). The burden of caring is more likely to fall on the mother. McDonald and Mackay (1996) found that among 217 families caring for people with severe learning disabilities in a H&SSB area in Northern Ireland the mother was seven times more likely to be the sole carer than the father. With respect to community care women are the main carers (Seltzer, et al. 1995; Smith, et al. 1995) and they may be exposed to exploitation from health and social care systems that use them to bridge service gaps.

Families of disabled children face financial burdens that are not always met by disability benefits and due to reduced income they are more likely to experience social deprivation (Glendinning, 1992).

In addition these families have inadequate respite with over a third not having access to this service (Carers National Association, 2000).

Siblings of the severely learning disabled children may also face inequalities with many having less contact with friends and increased levels of anxiety compared to other children (Coleby, 1995). In addition siblings are expected to contribute to caring and in some cases they may take on a major role in this, which has the potential to limit their life experiences and opportunities.

Children[4]

There is a potential for children with a learning disability to be disadvantaged in a range of areas that span from pre-school age through to the transition period when they leave school.

Many children are unable to access mainstream play and leisure activities. A survey in the Greater Belfast area of over 130 summer schemes and play and leisure facilities found that the biggest obstacles to inclusion of children with a learning disability were the lack of training for leaders; insufficient staff and resources (Thompson et al, 2000).

In a survey of 38 preschools of various types in the Greater Belfast area most were committed to enrolling children with autistic spectrum disorder but they felt that a lack of staffing could preclude this. A majority of staff felt they have had inadequate or no training to equip them to meet the children's particular needs and they reported a lack of knowledge and skills to help such children (McConkey and Burghri, 2003). This being the case access to preschool for these children is curtailed and thus an inequality exists in comparison to their non-disabled counterparts.

Many parents now expect services to be available in ordinary settings such as mainstream schools or leisure settings (Thompson, et al, 2000, O'Connor, et al, 2003). However, there is a potential for vulnerable children to be abused, bullied and exposed to discriminatory actions by other children, therefore a high degree of vigilance is required when such children are in public settings (Mencap, 2002).

Transition from school to adult services is a particular area of concern for parents (Ward et al, 2003). Commissioners and service providers are failing these children by not providing the same range of services and choices that are open to non-disabled young people, such as career guidance, further education, work experience and vocational training.

Physical Health

The DHSSPS (2002) under the 'Investing for Health' agenda notes that access to appropriate health care is a human right that should be equally available to all citizens. However, evidence would suggest this is not always the case with respect to people who have a learning disability.

A number of surveys in N.I. have indicated that there are high levels of unmet health needs among people with a learning disability (Marshall et al. 2000; McConkey et al., 2003). The significance of this is that while people with a learning disability have similar health needs to others in society if their health needs are not being met it follows that as a group they will suffer higher levels of morbidity. This is further confounded by the fact that many people with a learning disability have additional health needs to others in society (Hogg et al, 2000; Jansen et al. 2004) and within the population of people with a learning disability some (for instance people with Down syndrome) may have a higher incidence of physical health problems (Barr et al., 1999).

Other factors that may place people with a learning disability in a disadvantaged position with respect to their health status include: poor nutrition and polypharmacy (Beange, 2002); social disadvantage (Emerson et al., 2003); syndrome-specific

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[4] *The term children used in this review relates to learning disabled children and/or adolescents.*

disorders (Jansen et al., 2004); and various risk factors associated with the complex health needs that have become increasingly common as survival rates for those with profound and severe disabilities has increased (Wake, 2003).

There is growing evidence too that people with a learning disability do not access health promotion and health screening services to the same extent as non-disabled peers (Department of Health, 2001).

Older people

Many older people with a learning disability are at particular risk of neglect, poor access to health care and marginalization within society (WHO, 2000; Thorpe, et al. 2000). In addition, among the learning disabled population older people have been found to have high rates of untreated illness (physical and mental health), under use of health services (Howells 1996; Patel, et al. 1993), and they have been found to receive less day and respite care (Cooper 1997).

Some people with Down's syndrome age prematurely (Zigman, et al. 2002) and life longevity is reduced for many people with severe and profound disabilities (Holland 2000; Rice and Robb 2004).

The fact that the National Service Framework for Older People (NSFOP) relates only to people over 65 excludes many learning disabled people who suffer age related problems at a younger age than others. It could be argued therefore that the NSFOP discriminates against older people with a learning disability. Under an equality agenda older people with a learning disability should have at least similar access to other people, but many will require this at a much younger age.

People who challenge

The stigma, which leads to people with a learning disability being segregated in many areas of life, is exaggerated when they have additional challenging behaviours[5].

A person who displays challenging behaviours is more likely to be socially isolated and excluded not only because of the behaviour they display, but also due to the barriers to their social interaction skills and development that challenging behaviours create (Johnson, 1987). Communication difficulties associated with challenging behaviours in people with a learning disability further hinders their social integration (Vig and Jedrysek 1995; Kevan 2003). Those with the most severe behavioural problems are also more likely to be excluded from day opportunities such as day care or school (Russell, 1997).

Challenging behaviour is probably the single most recurrent reason for people with a learning disability being institutionalised (Blacher 1994); this group of clients are frequently the last people to move out of institutional care (Allen and Lowe 1995) and the ones most likely to be admitted to hospitals for specialist assessment and treatment (Slevin et al, 2002, Taggart, 2003). This indicates that there is an inequality in the provision of community care in that adequate resources are limited, or absent, and thus the needs of this client group may not be met (McConkey et al, 2003).

The inequality in community care provision for people with a learning disability has traditionally been dealt with in two ways. One is the use of hospitals to meet their needs. This may be for prolonged periods, or take the form of frequent repeated

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[5] *The term challenging behaviour as used here refers to people who challenge either due to behavioural causation (learned behaviour); mental health problems or both.*

admissions (so called revolving door admissions). Either of these may be seen as a breach of the Disability Discrimination Act (1995) (DDA) as it could be interpreted that a community 'service' is not being provided to meet such clients needs. Discrimination is prohibited under the DDA if a disabled person is treated less favourably in the standard of service they receive, or the service provider fails to make reasonable adjustments to allow the user to make use of a service (see later).

The second main mode of treatment in the management of challenging behaviours in those with a learning disability is psychopharmacology (Aman 2000; Emerson et al. 2000). The prescribing of more than one of these drugs (i.e. polypharmacy) to an individual is common (Fleming, et al. 1996). Medications are often used as a long-term management strategy without adequate review and many individuals are maintained on maximum dosages (Wressel et al., 1990; Fleming et al, 1996). Additionally, psycho-active drug regimes have been employed in isolation from alternative strategies (i.e. behavioural, educational and environmental) to manage challenging behaviours (Ahmed et al., 2000); but the greatest inequality that may result from the prolonged use of maximum dosages of these drugs is that they can prematurely end lives (Wolfensberger,1994).

Conclusions

There is ample evidence to demonstrate that people with a learning disability do not have access to the same range of health and social services and opportunities as their non-disabled age-peers. In the past this was explained by invoking their disability and excused on the grounds that special services were provided for them instead. However changed perspectives now demand that greater attention is paid to potential inequalities and action taken to address them.

Human Rights and Discriminatory practices

People with disabilities may face more fundamental inequalities, foremost of which is the right to life.

The European Convention for the Protection of Human Rights and Fundamental Freedoms is enshrined within the Human Rights Act (1998). At the centre of the human rights agenda is the fundamental principle that human beings have value and should be treated equally based on the fact that they are *human beings* first and foremost; human worth is not based on either capacity or incapacity (Declaration of Rights of Disabled People, 1975; Cherry, 1997).

However these rights can be overturned in the case of people with severe disabilities under the principle of '*best interests*'. For example the presence of a congenital abnormality provides grounds for abortion in many countries.

However this principle can also be invoked after birth. The usual circumstances when this takes place is when a physician decides that a treatment is warranted, or alternatively the withholding of treatment is warranted in the '*best interests*' of the client/patient. There have been numerous reported incidences when such actions have been upheld under the law, sometimes against the wishes (or consent) of the learning disabled person and their family. Such actions range from hospitalisation, to sterilization and in the most extreme cases life and death decisions. Diesfeld (2001) details a number of these events, for example:

- David Glass was a 12-year old boy with multiple disabilities. Following a tonsillectomy in hospital he developed infections and staff who believed he was dying, against his mothers wishes, commenced David on a diamorphine infusion (which potentially would hasten his death). This led to actual violence taking place between David's family and two doctors, which led to criminal actions against David's family members. As Diesfield (2001) points out it is improbable that medical staff would commence diamorphine on a non-learning disabled 12-year old, certainly not against the wishes of his parents.
- A 23-year old man 'R' who attended a day centre was deteriorating physically. Based on his low state of awareness and his deterioration a doctor signed a 'do not resuscitate' (DNR) order regarding R. Day-centre staff disagreed and based on assessments of his quality of life contested the DNR order through a judicial review. However, the outcome was that the NHS were authorised to proceed with the DNR, and the withholding of antibiotics based on so-called 'best interests'.
- J a 5-month old child with profound learning disabilities and multiple sensory and physical disabilities required ventilation to maintain life. However, doctors decided that should J require this again in the future it would be inappropriate to provide the ventilation. Best interest principles were used in court and the decision was that it would not be against the law to withhold artificial ventilation for J should he require it in the future.

There have been many similar decisions and as Diesfeld (2001, 390) points out 'these cases demonstrate the court's willingness, for over a decade, to make decisions to shorten the lives of infants with disabilities, based on obscure and conflicting notions of best interests.'

To date there have been no dramatic cases of discrimination reported in Northern Ireland - such as those involving life and death - that have been reported elsewhere. However, the potential for such occurrences does exist with the increasing number of severely disabled people who now survive. And questions do need to be asked here with regard to the inequalities that may exist in Northern Ireland as detailed in the first part of this section, for example are Trusts in breach of the DDA and Human Rights if they:

- Fail to provide an adequate community support team for a person with challenging behaviours?
- Exclude a person from day facilities or school because they do not have a nurse to care for the complex health needs of him/her?
- Maintaining a person in hospital because they do not have a facility in the community for a client to resettle to?
- Denying access to health screening and treatment for a person by virtue of inaccessibility or exclusionary practice?
- Not having in place services to adequately meet the needs of older learning disabled people?
- Failing to provide family support, for example respite?

In theory each of these is unlawful under the Disability Discrimination Act as they would represent a failure to provide an adequate service, a criteria that is discriminatory. With increasing litigation within society it may be only a matter of time until a client or family member legally challenges such service deficits.

Moreover, there are loopholes that have been frequently used to avoid the implementation of the DDA for learning disabled people. For example, it is not considered discrimination if an action is undertaken for the safety of the person or other people. Secondly, it is not discriminatory if the service provider reasonably considers that a person is incapable of giving 'informed consent'. For example there are well documented cases where people with a learning disability have had treatments such as being hospitalised against their will without use of Mental Health Legislation. The important fact here is that such a person is denied the right of appeal that others have who are admitted under Mental Health Legislation (Diesfeld, 2000).

Addressing Human Rights Issues

If institutionalised discrimination against people with a learning disability is evident in practice there remains an onus on government and through them service commissioners and providers (including the private sector) to address human rights and equality issues. This needs to be done at micro and macro-levels. Principles that guide services should be based on inclusion, empowerment and autonomy, justice and least restrictive practices (Gooding, 1995; Department of Health, 2001).

The Northern Ireland Act (1998) in Section 75 places a duty on public authorities to promote equality of opportunity in carrying out their functions and they must undertake an Equality Impact Assessment to determine if there are any negative impacts on the nine specified categories of which disability is one. If there are, then steps must be taken to reduced the impact (see Appendix 1.1).

While addressing human rights issues by legislative means is useful there is also the matter of people's 'mind sets' and their attitudes, which are notoriously difficult to change. Various commentators have noted that legislative implementation needs to be combined with:

- Education of clinical staff who may discriminate against learning disabled people based on misleading 'best principle' rationale
- Pushing forward the inclusion agenda by providing more integrated housing, education and day opportunities
- Learning disability awareness raising through schools as evidence suggests negative attitudes are formed early in life, and when developed such attitudes are extremely difficult to change
- Use of various local and mass media to raise the equality agenda for people with a learning disability
- Raising awareness across agencies of the need to counter inequality
- Raising awareness within associated services e.g. general hospitals, mental health services regarding countering inequality for people with a learning disability

There are promising indications that Government is addressing these issues.

Targeting Social Needs (DHSS&PS, 2001-2003) aims to address inequality by targeting those most in need. This action plan aims to improve access to services for disadvantaged people, to promote policies that reduce inequalities, and to monitor and measure how inequalities are being reduced.

Likewise, Investing for Health (DHSS&PS, 2002) aims to provide equal access and improved health for all in society, including those that are disadvantaged.

These are useful government initiatives and they do aim to address need and inequality across all society (a virtuous aim in itself) but past experience has shown that there is a need for persistent and frequent lobbying of government departments with respect to the needs of learning disabled people otherwise the concept of learning disability as a *Cinderella Service* will perpetuate.

At a more micro-level, the involvement of various stakeholders in service developments and addressing service problems is a good guiding principle. Fyson and Simons (2003) refer to the value of involving all relevant stakeholders in the development and implementation of Valuing People (DoH, 2001). This is particularly relevant to the involvement of service users. However persons with a learning disability need to have access to advocacy services in order to ensure their views are adequately represented and that they are able to access their rights.

Conclusions

The rights of people with a learning disability should be upheld by promoting choice, inclusion, independence, person-centred planning, addressing inequalities in housing and employment and by promoting creative day opportunity schemes. Empowerment, autonomy and justice should be guiding philosophies embedded within services. People with a learning disability have a right to equality based on our common humanity and a disability should not override this inherent right.

Possible Inequities in service provision

In this third part, we explore possible inequities in service provision both within Northern Ireland and in comparison between Northern Ireland and other countries of the United Kingdom and the Republic of Ireland.

This is a somewhat hazardous undertaking and our conclusions are tempered with many cautions. These arise primarily because of the poor quality of information that is generally available about the services provided and the actual numbers of people availing of them. Very often this data is only available for particular localities and it can be misleading to extrapolate this to provide national indicators.

Secondly there have been few studies that have explicitly compared service provision across different countries using the same criteria and instruments. This would help to ensure that comparisons are 'like-with-like'.

Third, there can be marked differences in the way services are provided in different countries and in the clients availing of them although similar names and descriptions are used.

Fourthly, comparative data can suggest that attaining the level of service provided in another country is adequate when in fact all countries or areas fall short of what is required.

With those provisos in mind, there do appear to be some marked differences in Northern Irish service provision. (Some may feel that this review is somewhat imbalanced in that aspects are not listed of service delivery in which Northern Ireland is comparable or better than elsewhere. However the listing is not meant to be comprehensive but rather to focus on possible deficits.)

- Northern Ireland has the highest proportion of people resident in long-stay hospitals and also has the single largest hospital in these islands. (15 beds per 1 million population in England and Wales; 163 beds per 1 million in Scotland and 264 beds per 1 million in Northern Ireland). All long-stay hospitals are due to close in England in 2004 and in Scotland by 2005.

- There are many more beds provided (or to be provided) in Northern Irish hospitals for assessment and treatment admissions (estimated 203 beds or 11.9 per 10,000 population) compared to Scotland (3.98 per 100,000 population) (Scottish Executive, 2004).
- In Northern Ireland over one quarter of people with a learning disability surveyed by McConkey et al (2000, 2002, 2003ab) lived in nursing homes. The proportion of nursing home places is higher here than in England and Wales where in 1997, just 7% of their places were in nursing homes (Emerson and Hatton, 2000). However the proportion of nursing home places varied within Northern Ireland; the NHSSB having the highest proportion (46%) and the WHSSB the lowest (21%).
- The proportion of people in supported housing within Northern Ireland is lower than Great Britain although there is wide variation across the four Boards; with EHSSB having the highest proportion (31%) and WHSSB and SHSSB the lowest (4%).
- None of the Trusts in Northern Ireland achieve the minimum number of residential places that the Department of Health has suggested for England and Wales, namely 15.5 places per 10,000. Again there is wide variation across the 11 community HSS Trust from 6.8 places per 10,000 to 13.8 places per 10,000.
- With respect to day opportunities, there are more people with a learning disability attending day centres in Northern Ireland (23.5 per 10,000 of total population) than in Scotland (15.1 per 10,000) and England (12.0 per 10,000) (McConkey, 2004). This may be viewed positively in that larger numbers of people have access to day centres and may redress the imbalance in the provision of residential places noted above. On the other hand, it could that Northern Irish people have less access to further education, supported employment and 'ordinary' leisure opportunities in comparison to people in Britain (Department of Health, 2001).
- In Great Britain not only do more people with a learning disability attend further education colleges (5.7% compared to 4.1% in Northern Ireland but more are enrolled on a full-time basis (45% compared to 11%) (DFHET, 2000). This option is not available in the Republic of Ireland.
- Although there are no centrally collated statistics in Northern Ireland, there appear to more opportunities for people with a learning disability to be in supported employment in Great Britain and the Republic of Ireland (Beyer and Kilsby, 1997: Health Research Board, 2003; McConkey, 2004).

Conclusions

- Overall in Northern Ireland there is an over-reliance on larger congregated living arrangements for people with a learning disability (either community based or hospital located) with fewer 'ordinary living' type accommodation in comparison to Britain.
- Similarly there has been a greater investment in specialist day centres.
- There can be wide variation across HSS Boards and Trusts in Northern Ireland in the type of services available to people with a learning disability.

Future Prospects

A review of this sort is in danger of underplaying the many positive achievements that have occurred within services for people with disabilities in Northern Ireland over the past decade and more. Hence we end by highlighting some of the most notable advances in services.

- An increase of 78% in Health and Social Services spending on this client group since 1996.
- The increased resources provided by Education and Library Boards to special schools and units, and in support of children with statements of special educational needs in mainstream schools.
- The increased number of children with a learning disability attending mainstream preschools, nursery and primary schools.
- The increase in the number of Allied Health Professionals and other staff working with children and families.
- The wider range of short-break options available to families and the discontinuing of hospital provision to meet this need.
- The reduction by 300 in the numbers of people living in long-stay hospitals since 1994.
- The increased diversity of accommodation and support options available to people with a learning disability and the numbers with tenancy agreements to their accommodation.
- Increased availability of further education, vocational training and employment options through European funding allied with government funding.
- The improved range and level of social security benefits available to people with a learning disability and their carers.
- The greater acceptance by society of the rights of people with a learning disability and their willingness to include in community life.

These improvements demonstrate that change is possible. They are also a reminder that the changes required in the future are but a continuation of what has largely begun. The foundations have been laid for the new buildings.

References

Allen, D. & K. Lowe (1995). Providing intensive community support to people with learning disabilities and challenging behaviour: a preliminary analysis of outcomes and cost. *Journal of Intellectual Disability Research*, 39, 67-82.

Aman, M. G., Alvarez, N, Benefield, W, Green, G, King, B H, Reiss, S, Rojahn, J & Szymanski, L (2000). Special issue, Expert consensus guideline series Treatment of psychiatric and behavioural problems in mental retardation. *American Journal on Mental Retardation*, 105.

Andersson, B. (1993). Depression and Anxiety in families with a mentally handicapped child. *International Journal of Rehabilitation Research*, 16, 165-169.

Bailey, N.M. and Cooper, S-A. (1997) The current provision of specialist health services to people with learning disabilities in England and Wales. *Journal of Intellectual Disability Research*, 41,52-59.
Bankhead, I. (2004) Learning Disability and Mental Health Legislation. Paper prepared for the Review of Mental Health and Learning Disability (Northern Ireland)

Beange, H (2002) Epidemiological issues. In Prasher, V.P. & Janicki, M. (eds.) *Physical health of adults with intellectual disabilities.* London, Blackwell Publishing / IASSID

Beyer, S. and Kilsby. M. (1997). Supported employment in Britain. *Tizard Learning Disability Review*, 2,2, 6-14.

Bickenbach, J.E., Chatterji, S., Badley, E.M. and Ustin, T.B. (1999) Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social Science and Medicine*, 48, 1173-1187.

Blacher, J. (1994). *Placement and its consequences for families with children who have mental retardation. When there is no place like home: options for children living apart from their natural families.* Baltimore, Paul H. Brooks, pages 213-243.

Booth, C.L. & Kelly, J.F. (1999). Child care and employment in relation to infants' disabilities and risk factors. *American Journal on Mental Retardation*, 104, 117-130.

British Psychological Society (2001) *Learning Disability: Definitions and Contexts.* Leicester: British Psychological Society.

Cassidy, G., Martin, D.M., Martin G.H.B. & Roy, A. (2002) Health checks for people with learning disabilities: community learning disability teams working with general practitioners and primary care teams. *Journal of Learning Disabilities*, 6, 123-136.

Cherry, C. (1997) Health care, human worth and limits of the particular. *Journal of Medical Ethics,* 23, 310-314

Coleby, M. (1995). The school-aged siblings of children with disabilities. *Developmental Medicine and Child Neurology* 37, 415-426.

Cooper, S. A. (1997b). Deficient health and social services for elderly people with learning disabilities. *Journal of Intellectual Disability Research* 41, 331-338

Declaration of Rights of Disabled People (1975) Proclaimed by the General Assembly of the United Nations, 9 December.

Department of Health (2001) *Valuing People: A new strategy for the 21st Century.* London: Department of Health.

DHSS&PS (2002) *Investing in Health*, Belfast: DHSS&PS

DHSS&PS (2001-2003) *Action Plan, New TSN*. Belfast: DHSS&PS

Department of Higher and Further Education and Training (2000) *Participation and provision for students with learning difficulties and/or learning disabilities (SLDD) in the further education sector in Northern Ireland.* Belfast.

Diesfeld, K (2000) Neither consenting nor protesting: an ethical analysis of a man with autism. *Journal of Medical Ethic,* _26, 277-281.

Diesfeld, K (2001) Disability matters in medical law. *Journal of Medical Ethics*, 27, 388-392.

Disability Discrimination Act (1995) London: HMSO

Dixon, P. (2003). *Modelling the Distribution of Services for People with Learning Disabilities in Northern Ireland.* Belfast: DHSSPS

Dobson, B. and Middleton, S. (1998) *Paying to care: The cost of childhood disability*. York: Joseph Rowntree Foundation.

EHSSB (1996) A model of community based services for people with learning disabilities. Belfast: EHSSB.

Emerson, E. & Hatton, C. (2000) Residential supports for people with learning disabilities in 1997 in England. *Tizard Learning Disability Review*, 5, 41-44.

Emerson, E., J. Robertson, et al. (2000). Treatment and Management of Challenging Behaviours in Residential Settings. *Journal of Applied Research in Intellectual Disabilities* 13, 197-215.

Fay, M.T. et al (1999) *The cost of the troubles study.* Derry Londonderry: INCORE.

Felce, D. (1996) Community housing costs. Tizard learning Disability Review, 1,1, 4-11.

Fleming, I., A. Caine, et al. (1996). Aspects of the use of psychoactive medication among people with intellectual disabilities who have been resettled from long-stay hospitals into dispersed housing. *Journal of Applied Research in Intellectual Disabilities*, 9, 194-205.

Foundation for People with Learning Disabilities (2000) *Learning Disabilities: The Fundamental Facts*. London: Mental Health Foundation.

Fox, D. & Wilson D. (1999) Parents' experiences of general; hospital admission for adults with learning disabilities. *Journal of Clinical Nursing*, 8:610-614.

Fryson, R. & Simons, K. (2003) Strategies for change: making Valuing People a reality. *British Journal of Learning Disabilities*, 13, 153-158

Glendinning, C. (1992). *The costs of informal care: Looking inside the household*, London, HMSO.

Gooding, C (1995) *Blackstone's guide to the Disability Discrimination Act*. London: Blackstone Press.

Hart, S. (1999) 'Meaningful choices: consent to treatment in general health care settings for people with learning disabilities'. *Journal of Learning Disabilities,* 3, 20-6.

Hatton, C., Elliot, J. & Emerson, E. (2003) *Key highlights of research evidence on the health of people with learning disabilities.* (available at http://www.doh.gov.uk/vpst/latestnews.htm#newdocs)

Health Research Board (2003) *National Intellectual Disability Database: Annual report 2001.* Dublin, Health Research Board.

Hill, C. & Dagnan, D. (2002) Helping attributions, emotions and coping styles in response to people with learning disabilities and challenging behaviour. *Journal of Learning Disabilities,* 6, 363-372.

Hogg, J., Northfield, J. & Turnbull, J. (2000) *Cancer and people with learning disabilities.* British Institute of Learning Disabilities, Kidderminster.

Holland, A. J. (2000). Ageing and learning disability. *British Journal of Psychiatry* 176, 26-31

Howells, G. (1996). Situations vacant: doctors required to provide care for people with learning disabilities. *British Journal of General Practice*, 46: 59-60

Human Rights Act (1998) London: HMSO

Ilkes, I. (2003) Becoming a learning organisation: a precondition for person centred services to people with learning disabilities. *Journal of Learning Disabilities,* 7, 65-77.

Jansen, D., Krol, B., Groothoof, J & Post, D. (2004) People with Intellectual disabilities and their health problems: a review of comparative studies. *Journal of Intellectual Disability Research*, 48, 93-102.

Jarbrink, K. & Knapp, M. (1999) *The costs of autistic spectrum disorder: an exploratory study.* London: Mental Health Foundation.

Jones, E. et al (2000) Evaluation of the dissemination of Active Support training and training trainers. *Journal of Applied Research in Intellectual Disabilities*,14, 2, 79-99

Johnson, D. (1987). Nonverbal learning disabilities. *Pediatric Annals* 16, 133-144.

Kavanagh, S.M. and Opit, L.J (1999) The prevalence and balance of care for intellectual disability: secondary analyses of the OPCS disability services. *Journal of Applied Research in Intellectual Disabilities,* 12, 127-148

Kevan, F. (2003). Challenging behaviour and communication difficulties. *British Journal of Learning Disabilities* 31, 75-80.

Louihala, P. (1995) Risk indicators of mental retardation: changes between 1967 and 1981. *Developmental Medicine and Child Neurology*, 37, 631-636.

McConkey, R. (2003) Information needs of parents about learning disabilities. *Journal of Learning Disabilities*, 7, 211-219.

McConkey, R. and Barr, O. (2000) *Future Housing and Support Needs of People with Learning Disabilities and their Families:* A Report to the Northern Health and Social Services Board and the Northern Ireland Housing Executive. Belfast: NIHE.

McConkey, R., Barr, O., Fleming, P. & Milligan, V. (2003). *Evaluation of Challenge 2000: Health Screening and Health Promotion Service provided by North & West Locality Consortium (Belfast) to people with learning disabilities. (Clifton Street Surgery, Belfast and EHSSB).*

McConkey, R., Madden, E. & Milligan, V. (2003b) *Future housing and support options for people with learning disabilities in the E.H.S.S.B. area.* Belfast: NIHE.

McConkey, R., Milligan, V. & Madden, E. (2003a) *Future housing and support options for people with learning disabilities in the S.H.S.S.B. area.* Belfast: NIHE.

McConkey, R. & McConaghie, J. (2001) *Supported Living: An evaluation of three schemes in Northern Ireland for people with learning disabilities.* Ballymoney: Triangle Housing Association.

McConkey, R., McConaghie, J., Mezza, F. & Wilson, J. (2000) *Moving on from Muckamore Abbey Hospital: The outcomes and lessons as perceived by people with learning disabilities; their key-workers, care managers and relatives.* Belfast: EHSSB.

McConkey, R., Spollen, M. & Jamison, J. (2003). *Administrative prevalence of learning disability in Northern Ireland.* Belfast, DHSSPS.

McDonald, G. & Mackay, D. (1996) The prevalence of learning disability in a Health and Social Services Board in N. Ireland. *Journal of Intellectual Disability Research,* 40, 550-556

Mansell, J. and Beadle-Brown, J. (2004) Person-centred planning or person-centred action? Policy and practice in elanring disability services. *Journal of Applied Research in Intellectual Disability,*

MENCAP, (2001) *Equal lives for people with learning disabilities.* Belfast: MENCAP

Murray, A. and Heatherington, N. (1998) Social work: leading for following in challenging times for learning disability? In *Social work and Social Change in Northern Ireland: Issues for contemporary practice.* London: CCETSW.

National Assembly of Wales (2001) *Fulfilling the Promises: A framework for services for people with learning disabilities in Wales*. Cardiff: National Assembly.

National Health Service Executive (1998) *Signposts for success in commissioning and providing health services for people with learning disabilities*. Department of Health, London.

NHSSB (1998) *Promoting ability: a strategy for the development of care for people with a learning disability*. Ballymena: NHSSB.

O'Brien, C.L., O'Brien, J. & Mount, B. (1997) Person-centred planning has arrived ... or has it? *Mental Retardation*, 35, 480-484.

O'Connor, U., Hartrop, B. & McConkey, R. (2003) *Parental attitudes to the statutory assessment and statementing on special educational needs*. Belfast, DENI.

Patel, P., D. Goldberg, et al. (1993). Psychiatric morbidity in older people with moderate and severe learning disabilities II: The prevalence study. *British Journal of Psychiatry*, 163, 481-491

Rice, J. and A. Robb (2004). Learning to listen. *Nursing Older people* 15, 10-13

Roeleveld,N., Zielhuis, G.A. & Gabreels, F. (1997) The prevalence of mental retardation: a critical review of recent literature. *Developmental Medicine and Child Neurology*, 39, 125-132.

Rowe, D. & Rudkin, A. (1999) A systematic review of the qualitative evidence for the use of lifestyle planning in people with learning disabilities. *Journal of Learning Disabilities*, 3, 148-158.

Russell, P. (1997). Don't forget us! Messages from the Mental Health Foundation Committee's Report on Service for Children with Learning Disabilities and Severe Challenging Behaviour. *British Journal of Special Education* 24, 60-65.

Scottish Executive (2000) *The same as you? A review of services for people with learning disabilities*. Edinburgh: HMSO.

Scottish Executive (2004) *Home at Last? Report of the short-life working group on hospital closure and service reprovision*. Edinburgh: Stationery Office.

Seltzer, M. M., J. S. Greenberg, et al. (1995). A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation. *Psychology and Aging* 10, 64-75.

SHSSB (2000) *Services for people with a learning disability. A strategic review – proposals for future service provision*. Armagh: SHSSB.

Sloper, P. (1999) Models of service support for parents of disabled children. What do we know? What do we need to know? *Child: Care, Health and Development*, 25, 85-99

Smith, G. C., Tobin, S.S. et al. (1995). Elderly mothers caring at home for offspring with mental retardation: a model of permanency planning. *American Journal on Mental Retardation* 99, 487-499.

Smyth, M. et al (2001) *Caring through the troubles: Health and Social Services in North and West Belfast*. Belfast: N&W Belfast HSS Trust.

Smyth, M. et al (2004) *The impact of political conflict on children in Northern Ireland*. Belfast: Institute for Conflict Research.

Thorpe, L., P. Davidson, et al. (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Biobehavioural Issues.* Geneva, Switzerland, WHO

Truesdale. M. and McConkey (2001) Maternal health and stress in families with a child who has multiple disabilities. *Child Care in Practice*, 7, 143-152

Twigg, J. & Atkin, K. (1994). *Carers perceived: policy and practice in informal care.* Buckingham, Philadelphia: Open University Press.

Vig, S. and E. Jedrysek (1995). Adaptive behaviour of young urban children with developmental disabilities. *Mental Retardation*, 33, 90-98.

Wake, E. (2003) Profound and multiple disability. In Gates, B. (ed.) *Learning disabilities: towards inclusion.* 4th ed. Edinburgh: Churchill Livingstone.

Ward, L., Heslop, P., Mallett, R., and Simons, K. (2003) Transition: The experiences of young people with learning disabilities and their families in England. *Tizard Learning Disability Review*, 8, 19-28.

WHSSB (2000) *Social Care Review 1999-2000.* L'Derry: WHSSB.

WHO (2000). *Ageing and Intellectual Disabilities - Improving Longevity and Promoting Healthy Aging: Summative Report*. Geneva, Switzerland, World Health Organization

Wolfensberger, W. (1994). The growing threat to the lives of handicapped people in the context of modernistic values. *Disability and Society* 9, 395-412.

Wressel, S. E., S. P. Tyrer, et al. (1990). Reduction in anti-psychotic drug dosage in mentally handicapped patients: A hospital study. *British Journal of Psychiatry*, 157: 101–106.

Zigman, W. B., N. Schupf, et al. (2002). Incidence and temporal patterns of adaptive behaviour change in adults with mental retardation. *American Journal on Mental Retardation* 107,161-174

Appendix 1.1: Legislation in Northern Ireland

Most of the recent legislation in N. Ireland has followed on from Parliamentary Bills first introduced at Westminster and this is usually done by Orders in Council. The main extant Orders (arranged by date order) affecting people with a learning disability are:

The Mental Health (NI) Order (1986)

Under this Order people with a learning disability (referred to in the Order as mental handicap/mental impairment) can be detained in hospital for assessment and treatment if they are suffering from a mental disorder, the nature and degree of which presents a substantial risk to themselves, and when failure to detain them creates a substantial likelihood of serious physical harm to themselves or others.

The Education and Libraries Boards (NI) Order (1986/1987) and Education (NI) Order 1996.

Under these Orders, Education and Library Boards have a duty to identify and assess children in their area who have special education needs and children who they think have, or will have, special education needs. If the assessment finds that a child has special education needs, the Education and Library Board must issue a statement explaining these needs which must also detail the special arrangements being made by the Education and Library Board to meet those needs.

The 1996 Order provides a legal framework for the assessment and development of special education needs. It is accompanied by a Code of Practice on the Identification and Assessment of Special Education Needs (Department of Education for Northern Ireland, 1997), based on its equivalent developed in England and Wales (DfEE, 1994). This code provides detailed guidance on five stages of assessment,

The Disabled Persons (NI) Act" (1989).

The Chronically Sick and Disabled Persons (NI) Act 1978 was amended by the Disabled Person (NI) Act 1989. The 1989 Act, in addition to the provisions in the 1978 Act, requires Health and Social Services Trusts to assess young people with disabilities, at the time they leave school, for a range of welfare services as outlined in the Chronically Sick and Disabled Persons (NI) Act 1978. The Trusts are also expected to give appropriate advice about matters such as employment and further education.

Section 5 of the Disabled Persons (NI) Act 1989 requires Education and Library Boards to notify the relevant Trust at the time of the first annual review of a statement following the child's 14th birthday, or at a time of a reassessment after that birthday, whichever is earlier. This notification is required in order for Trusts to consider the young person's needs for social services after they have left school. Education and Library Boards are also required to notify the Trust between twelve and eight months before the actual date of ceasing full-time education.

The Disabled Persons (NI) Act 1989 also gives disabled people rights to representation, to assessment of their needs, and to information and counselling. The statutory provisions relating to representation are provided in Sections 1 and 2 of the 1988 Act and intended to give the same rights to disabled people in Northern Ireland as that given in Great Britain by the Disabled Persons (Services, Consultation, and Representation) Act 1986. For example, Section 2 requires Boards or Trusts to make arrangements for social services to meet the needs of disabled people, including practical assistance in the home, transport arrangements to and from home, home adaptations, holidays and help obtaining a telephone. However, ten years on, these two sections have not yet been implemented in N. Ireland.

Carers of disabled people, including those caring for disabled young people, have the right to have their ability to care taken into account (section 8) and the right to ask for an assessment of the needs of the disabled person (section 4).

Health and Personal Social Services (NI) Orders 1991 and 1994.

Under these Orders, Health and Social Services Boards are responsible for assessing the health and social welfare needs of their resident population (including disabled young people and adults) and for commissioning services to meet these needs.

These Orders brought about the purchaser/provider split in the organisation of health and personal social services, with Health and Social Services Boards "purchasing" services for their resident population and HSS Trusts "providing" services which were agreed through contracts with Health and Social Services Boards. The Trusts may in turn sub-contract with private and voluntary organisations for services.

The Children Order (N.I.) (1995)

This Order was made in March 1995 and most of its provisions commenced on November 1996. It brings together most public and private law relating to children and establishes a new approach to services provided by Health and Social Services Trusts for children and their families.

The Children (NI) Order 1995 provides a legal framework for the provision of social care services for disabled children and their families and seeks to ensure the integration of these services. They are to be recognised as children first with the right to have their particular needs met by the provision of services. Young people with disabilities, up to the age of 18 (or 21 in some circumstances), are included in the Order's definition of "children in need" (Article 17).

The Order defines a child as disabled if he or she is:

"blind, deaf, dumb or suffering from mental disorder of any kind or substantially or permanently handicapped by illness, injury or congenital deformity or such other disability as may be described."

The language used is archaic and may be seen as stigmatising, but it is the legal definition to be adhered to by Trusts providing services and assessing the needs of disabled children. Disabled children, as children in need, are entitled to services necessary to safeguard and promote their welfare. Trusts are required to take reasonable steps to identify children in need in their area and to assess the needs of such children.

Northern Ireland Act 1998

Section 75 of the Northern Ireland Act 1998 states:

"A public authority shall, in carrying out its functions to Northern Ireland, have due regard to the need to promote equality of opportunity-

Between persons of different religious belief, political opinion, religious group;, age, marital status or sexual orientation;

Between men and women generally;

Between persons with a disability* and persons without; and

Between persons with dependants and persons without".

**Disability has the same meaning as in the Disability Discrimination Act 1995 (see below).*

Following on from Section 75, public authorities must now undertake Equality Impact Assessments. An Equality Impact Assessment (EQIA) is a thorough and systematic analysis of a policy. The purpose of carrying out an EQIA is to identify whether there are differences in the way a policy impacts upon the nine categories stipulated under Section 75 and whether these differences are adverse i.e. do they have a negative impact on any of the equality categories. If there are negative impacts then the public body must consider how these should be addressed. This may involve developing new measures to reduce the negative impact or developing new measures that more effectively promote equality of opportunity.

This Act also established the Equality Commission for Northern Ireland which subsumed the Northern Ireland Disability Council and which undertakes the same functions as the Disability Rights Commission in Great Britain.

Other UK legislation:

Three further pieces of legislation also have implication for services

Carers Recognition and Service Act (1995) :

This requires HSS Trusts to undertake an assessment of carer's needs; to provide information about services and arrange means whereby their needs can be met.

Community Care Direct Payments Act (1996)

This Act which is mandatory in N. Ireland from 1998, makes it possible for disabled people, including those with a learning disability, to have a Direct Payment from HSS Trusts, to pay for their community care services. The individual can use the money to buy or organise the kind of support that best suits them rather than use services provided by Trusts or other organisations on their behalf.

Disability Discrimination Act (1996)

This Act aims to ensure that disabled people have equal opportunities in terms of access to employment, buildings, and goods and services. It also requires schools, colleges and universities to provide information for people with disabilities and make suitable accommodation for their needs. There was initial debate about what constituted 'services' but parliamentary challenges have led to the affirmation that services include health and social services. Under the DDA it is illegal to discriminate by any of the following:

- refusal to provide a service
- treating a person less favourably in the standard of service, or how a service is provided
- providing a service in less favourable terms (e.g. failure to provide access for disabled people).

Under the DDA disabled people are defined as follows:

1. must have a physical or mental impairment
2. the impairment must adversely affect the individuals ability to carry out normal daily activities
3. the adverse effect must be substantial
4. the adverse effect must be long term.

Under the act the term impairment is defined as relating to the following aspects: mobility, dexterity, physical condition, continence, ability to lift, speech hearing or eyesight, cognition (memory, concentration and learning) and perception of risk. There seems little doubt that many people with a learning disability are 'disabled' under the DDA definition. It therefore follows that people with a learning disability should be protected under the DDA.

Appendix 1.2: International Terminology

The term 'learning disability' is unique to Britain and Ireland. It was introduced first by the Department of Health in 1991 in response to lobbying for changes in the term 'mental handicap'. Similarity the Northern Irish Review of Learning Disability in 1995 recommended *"the expression 'people with a learning disability' be adopted by the Department and by services in Northern Ireland".*

However this decision failed to take into account that the term 'learning disability' is widely used internationally and in North America in particular, to refer to people (mostly children) who experience specific problems in learning to read, write or in numeracy. This is a serious drawback in international dialogue. The term 'intellectual disability' is being increasingly used in academic and international publications.

The changed UK terminology did not extend to legislation. Hence current Orders, Acts and policy guidance variously refer to 'mental handicap', 'mental impairment' (both are defined in the Mental Health Order) and mental disorder (Children (NI) Order.

Moreover the wider public can be confused as to what the phrase 'learning disability' means. For example, over one quarter of the general public in Northern Ireland do not consider a learning disability to be a 'disability' – whereas 73% did (NI Omnibus survey January 2004.) However 90% of respondents in the Republic of Ireland rated it as a disability when the words 'intellectual' and 'mental' were added (NDA, 2002).

Alternative terms

Various terms have been used in the past and in different countries.

Mental Handicap This term was widely used in Ireland and Britain up until recently. The main objections to it centre on the word 'mental' and the confusion it brings with a 'mental illness'. Furthermore the word 'handicap' tends to conjure up images of people in wheelchairs.

Mental Retardation This term was popular in North America up until recently. Although this term does carry the connotation that these people are slow at learning, the problems surrounding the word 'mental' still remain. This term is used in International classifications such as ICD10 and DSM IV.

Developmental Disabilities This term is tending to replace 'mental retardation' in North America and elsewhere. It accurately reflects the reality of the disability (namely all aspects of development are affected). However, the term does not distinguish what we know as mental handicap from other developmental disabilities, such as cerebral palsy. The usefulness of the term with adults is dubious.

Intellectually Handicapped This term has been in use for some years, mainly in Australia and New Zealand. Technically, it is probably the most accurate, with its focus on intellectual competence, especially when the term intellect is used in its widest sense (i.e. the faculty of knowing, reasoning and understanding) and not taken solely as the scores on an intelligence test. However the latter point has led some to criticise this terminology on these grounds.

Intellectual Disability The World Health Organisation has adopted this term; making an important distinction between handicaps which tend to be acquired over time and disabilities which are usually present from birth and which may or may not become a handicap. This term is now being used increasingly internationally and especially by countries in the developing world as they begin to establish specialist services for these clients.

Learning Difficulties Recent British legislation in education has focused on this terminology and it is the preferred term of many self-advocates but there are still various shortcomings. Although accurate, the emphasis on learning could suggest that the problems are only educational in nature and are more applicable to children. Also, the word 'difficulties' may belittle the marked disabilities which some of these people may have.

Other terms have also been suggested by advocates and family members such as 'special people', ' special needs', 'slow developer' or 'slow learner'. These terms tend to be less stigmatising. However, if these terms are to be applied to people who are currently referred to as having a learning disability, there then exists the problem of what to call the many children who in educational terms are slow learners but who have no serious disability.

Appendix 1.3: Selected definitions of 'learning disability'.

International definitions of what is known as 'learning disability' include three elements all of which must be present:

- Significant impairment of intelligence that includes a reduced impairment to understand new or complex information, and to learn new skills.
- Deficits in social functioning or adaptive behaviour and a reduced ability to cope independently.
- The disability started before adulthood and has a lasting effect on development.

However the precise terminology used in definitions varies and there are significant problems in operationalising these definitions so that people can be reliably and validly classed as 'learning disabled.'

Northern Ireland

In Northern Ireland there has been relative consistency in the definitions used although the terminology is not always consistent. For example, mental handicap is defined in the Mental Health (NI) Order 1986 as:

"A state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning."

(The Order also defines 'severe mental handicap' in similar terms by substituting the word 'significant' with 'severe' – see Chapter 1.)

However this definition omits a key feature included in all international definitions, namely that the disability or impairment is present from childhood. Moreover the term 'development of mind' is impossible to define accurately (Foundation of People with Learning Disabilities, 2001).

Great Britain.

The Scottish Review of Learning Disability Services (Scottish Executive, 2001) considered it important for any definition to give an appropriate and meaningful description of the services ands supports individuals may need. Hence they state:

"People with learning disabilities have a significant life-long condition that started before adulthood, that affected their development and which means they need help to understand information; learn new skills; and to cope independently" (p.3).

Likewise the English Review (Department of Health, 2001) gave this definition:

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.*

European Union

The EU Monitoring and Advocacy Program of the Open Society Institute (2003) defined intellectual disability (also described as learning disability or mental retardation) as:

A lifelong condition, usually present from birth or which develops before the age of 18; is a permanent condition that is characterized by significantly lower than average intellectual ability; results in significant functional limitations in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills.

They go on to note that "a person with intellectual disability usually requires support in three or more of the following area of major life activity: self-care, receptive and expressive communication, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency. People with intellectual disabilities generally need a combination of special, interdisciplinary or generic services, individualized support, and other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated".

United States of America

DSM-IV Diagnostic and Statistical Manual of Mental Disorders

The American Psychiatric Association in their diagnostic classification defines mental retardation as:

(a) *significantly sub-average intellectual functioning: an IQ of approximately 70 or below on an individually measured administered IQ Test.*

(b) *Concurrent deficits or impairments in present adaptive functioning (i.e. the person's effectiveness in meeting the standards expected of 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.*

The American Association on Mental Retardation (2002) has been an international leader in defining and assessing people with 'mental retardation'. They define mental retardation as:

A disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disability originates before 18 years of age.

They go on to note five assumptions that are essential to the application of this definition.

1. "Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and behavioural factors.
3. Within an individual, limitations often co-exist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports,
5. With appropriate personalized supports over a sustained period, the life functioning to the person with mental retardation generally will improve".

Chapter 2:

Staffing Issues in Learning Disability Services

This chapter deals with the critical issue of staffing within services. This is done both within specialist services for people with a learning disability but also the implications are explored for staff in mainstream services who may in the future have increased involvement with people who have a learning disability.

The recruitment of volunteer helpers is also considered as they have a crucial role to play in providing informal supports and facilitating social inclusion.

Particular attention is focussed on staff recruitment and retention, as these are presently proving difficult for service providers.

The chapter is divided into five sections.

Section 1 reviews the range of staff now involved in services and the main issues of concern.

Section 2 describes the role of past and future roles of volunteers.

Section 3 examines the recruitment and retention of staff in learning disability services.

Section 4 outlines the staffing implications arising from the changing nature of services.

Section 5 reviews the needs of staff working in mainstream services with people who have a learning disability.

The majority of the research studies quoted in this chapter are from English services. However several projects undertaken in Northern Ireland, while not focusing on staffing per se have nonetheless highlighted the need for awareness of staff reactions, knowledge and skills as these all impact on the services provided to people with a learning disability and their families.

The need is highlighted for more research on staffing issues.

Section 1: The range and impact of staff

As noted in Chapter 1, the past 20 years has seen considerable change in the structure and organisation of services provided to people with a learning disability. One consequence has been the creation of a wide range of staffing in services. These now include:

- Direct care staff in residences and day centres; many of whom have no formal qualification. Their role can also vary greatly depending on the size and type of facility.
- Professionals who have undertaken specific professional courses to work with people with a learning disability (e.g. Learning Disability Nursing)
- Staff from generically qualified professions which qualifies them to work with people with a learning disability on either a whole-time basis or as part of a more generic case-load. This category include social workers, clinical psychologists, Allied Health Professionals such as speech & language therapists, occupational therapists, physiotherapists and podiatrists, as well as teachers in special schools.
- Staff working in mainstream services who may come into contact with people with a learning disability such as health visitors, GPs, teachers and lecturers in Colleges of Further and Higher Education.
- Staff who take post qualification courses specific to people with a learning disability (e.g. Psychiatrists in learning disabilities)

Alongside the service developments, there have been changes in the demography of people with a learning disability. There is a growing number of older people often with increasing health and social care needs. The numbers of children and young adults with complex health needs in special schools and day services has increased. These place extra, and different, demands on staff.

The expectations of parents and people with a learning disability have also increased in relation to what services will provide. By its nature, the outcome of the present Review of Learning Disability services will introduce further changes in the structure, organisation, responsibilities and expectations of services. The availability and retention of the necessary numbers and grades of staff are central to effectively managing ongoing and future changes.

The impact of staffing

The human resources within any service provided to this client group are perhaps the major factor on its effectiveness. Research has demonstrated that the knowledge, attitudes and reactions of staff to the people they work with are key influences on service quality (Rose, 1999; Hill & Dagnan, 2002; Smith et al, 2002; Wanless & Jahoda, 2002).

Staffing costs are usually the largest recurrent expenditure within services and as such comprise a major investment. This investment is integral to the continued success of service provision and requires ongoing attention in order to maximise the contribution individuals and teams can make to lives of people with a learning disability and their families (Hatton et al., 1999; 2001).

In recent years concerns have been expressed in both USA and UK about the difficulties experienced in recruiting and retaining staff in the new styles of community-based services. For example, in the United States annual turn-over rates in community facilities have ranged from 34% to 71% compared to 18% turnover in large public institutions (Larson and Lakin, 1999). There is anecdotal evidence that similar experiences are now happening in Ireland both North and South and especially in the larger urban centres of population. This has major consequences for both service managers and for service recipients and threatens the development of more socially inclusive services.

There are marked advantages to maintaining consistency within the staff group in that it can contribute to increased continuity within service delivery (Hatton et al., 1999), the experience and knowledge and skills within staff members can grow, it offers a greater return for investment in training and reduced costs in recruitment as well as retention of staff.

A cohesive staff group with a commitment to the service and high staff morale also provides a stable platform for forward planning and service development. It has been shown that as staff become more experienced and undertake more specific training, they become more confident and skilled in working with people with a learning disability, in particular people in complex settings such as forensic or challenging behaviour services, or in relation to complex needs such as challenging behaviour, self injurious behaviour, offending and sexuality (McConkey & Ryan, 2001; Wanless & Jahoda, 2002; Taylor et al, 2003).

Some predictable and managed staff turnover is to be expected, and indeed is healthy, as it brings new staff, ideas and energy into services as people progress through their career, or as the structures of service provision alter. However, if the degree of staff turnover becomes unpredictable and unmanaged, a number of difficulties can result including difficulties in recruiting and retaining staff. This results in greater expenditure on recruitment, training and the increased need to supervise new staff (Hatton et al., 2001).

Frequent staff turnover can also contribute to inconsistency in the services provided and an inability to recruit the necessary staff may result in some services to people with a learning disability and their families being unavailable. Presently in Northern Ireland there appears to be particular dearth of speech and language therapists and clinical psychologists.

The frequent change in staff coupled with a lack of staff is also likely to result in increased pressure on the available staff and have a negative impact on their morale. In addition the inability to recruit and retain staff in community based services may make for difficulties in supporting people with more complex needs and lead to their admission or readmission to specialist hospital services (Seager et al., 2000; Taggart & McConkey, 2001).

Conclusions

The marked increases in the numbers and range of staff involved in the provision of services to people with a learning disability has also resulted in increased difficulties in recruiting and retaining staff. Nonetheless the calibre of staff is the biggest single influence on service effectiveness and quality.

Section 2: Volunteers

At the outset though we need to acknowledge the contribution that volunteers make in the lives of people with a learning disability.

Family carers

In a sense families of people with a learning disability are voluntary workers in that none of them chose a career as a carer and yet they give unstintingly in the quantity and quality of care they provide. Although it is impossible to accurately assess this financially, when it has been done for all carers in Northern Ireland (Carers UK, 2002a) and then pro rated for those likely to be caring for a child or adult with a learning disability, the total amount is in the order of £170 million per year which exceeds that spent by Health and Social Services (see chapter 1).

Moreover as British surveys have shown, parents of people with a learning disability are more often likely to be engaged in voluntary work to assist others than are other parents (Carers UK, 2002b).

Variations in volunteering

The term volunteer is used more often to describe individuals who freely give of their time and talents to provide services and supports usually to groups of people with disabilities. Possibly the largest cadre of volunteers are deployed in leisure and sporting activities. In Northern Ireland an estimated 4,000 children and adults with a learning disability are involved to some extent in leisure clubs such as Gateway (McConkey, 2004) and these are staffed mainly by volunteer workers; the numbers of which are not known.

In recent years there has been an increase in the number of befriending and advocacy schemes which also rely mainly on volunteers. Here they are usually linked with one or two individuals to provide informal social relationships and support in accessing community facilities. A recent survey in Northern Ireland identified this as the 5th most popular form of voluntary activity (VDA, 2000) involving a range of groups including young mothers, the elderly, those with mental health problems and young carers.

Holloway and Mawhinney (2002) estimated there were around 180 befriending schemes operating in Northern Ireland; most of which were linked to organisations that provided a wider range of services such as information and support, recreation and education and training. Of these around 14% focussed on people with a learning disability. The typical befrienders were females aged between 26 and 59 years with very few from ethnic minority groups. Overall the turn-over was low but as demand exceeded supply, many schemes reported difficulties recruiting sufficient number of befrienders. Most recruitment being done by word of mouth, leaflets and posters.

Another category of volunteer is people in mainstream settings such as preschools and summer schemes who enrol children and adults with a learning disability. Recent research in Northern Ireland has highlighted the need for training and ongoing support for these personnel to sustain and extend their willingness to include people with special needs (Thompson et al, 2000; McConkey and Burghri, 2003). Likewise teachers in mainstream schools and co-workers in businesses perform a similar function when people with a learning disability are placed in these settings.

The distinction between volunteer and paid staff can be blurred in fostering and family placement schemes in which a person with a learning disability is looked after by a host family in their home. Payments are made to cover the extras expense this entails although there is criticism of the low rates of pay on offer. However most volunteers in these schemes are not wanting to make money but continue because of the satisfaction and enjoyment they get from it (McConkey et al, 2004).

In all forms of voluntary work there is a recurring characteristic of the volunteers; many will have had a prior involvement with people who have a learning disability, either as a paid worker or through family members. For example, two-thirds of the placement providers in two schemes in Northern Ireland had experience in the care sector either as nurses, care assistants, domestics or classroom assistants (McConkey et al 2004).

Likewise a common outcome is the way the experience enriches the lives of the volunteers. A study of over 200 volunteers who supported athletes at the World Games of Special Olympics in Dublin identified four main outcomes; it was an enriching and worthwhile experience; they gained a greater understanding of people with a learning disability; it contributed to a national event in the life of the country and it emphasised people's talents not their disabilities (McConnell and McConnell, 2003).

Future prospects for volunteering

Surprisingly little research has been undertaken into volunteering and people with a learning disability. General surveys into volunteering in Ireland suggest that around one third of adult persons are engaged in some form of voluntary activity and that in Northern Ireland this figure has risen by 17% since 1995 (Volunteer Development Agency, 2001). Volunteers are more likely to be female, aged between 35-64 years; in full-time employment, middle class with no young children. The most popular areas for voluntary work are fund-raising; involvement in sport and recreation and religious organisations and around half are involved at least once a month. In all 6% of volunteers reported an involvement with people who have a learning disability. Many people find out about volunteering through their family and friends and most become volunteers because they were asked. The most common reason for not volunteering is lack of time (Ruddle and Harrison, 1999).

Concerns have been expressed about difficulties in recruiting volunteers for leisure and recreation clubs, befrienders and as placement providers (Holloway and Mawhinney, 2002; McConkey, 2004). It may be that more attention needs to be paid to training and induction of volunteers, targeting young people at school and College, and the payment of expenses. Ireland – North and South - has the highest percentage in Europe of volunteers not receiving out-of-pocket expenses (Volunteer Centre UK). Indeed many of the issues that affect the recruitment and retention of paid staff may also apply to volunteers.

The participation of volunteers within statutory services is especially low in Northern Ireland with only 6% working in this sector (Volunteer Development Agency, 2001) compared to 24% in a UK study (Davis-Smith, 1998). Greater partnership working between the statutory and voluntary sectors could lead to improvements in this (see Chapter 9).

Conclusions

Volunteers are in danger of being overlooked as services become more professionalised. Increased resources and efforts are required to sustain and expand schemes that support volunteers. This is one of the proven means of reducing the social exclusion and for increasing the quality of lives of people with a learning disability.

Section 3: Recruitment and retention of staff in learning disability services

Overall little attention appears to have been given to why people seek employment in services for people with a learning disability. Instead the majority of research has focused on factors that influence the retention of staff already working in services.

This issue is all the more difficult given the range of staff now employed in services. It may well be that factors influencing the recruitment and retention of speech and language therapists are different to those for part-time care assistants in residential homes. At present most research has focussed on single groups of staff and mainly direct care workers with few comparative studies across different types of staffing.

Recruitment

Although some commonality may be present in peoples' reason for wishing to work in learning disability services it is also probable that considerable differences may exist across the groups of staff outlined above.

Anecdotal information would indicate that some key reasons for entering services for people with a learning disability include: previous personal contact with people who have a learning disability, an interest in a career within health, social services or education based professions, the availability and perceived stability of employment, positive perceptions of what the work involves and the associated anticipation of job satisfaction.

The extent to which these views and perceptions are fulfilled has been reported to influence the retention of staff (Hatton et al, 1999; 2001) and they are also likely to impact on their recruitment. This will be further explored after the issues impacting on retention have been considered.

Whilst several professional groups have published their standards for staffing levels in relation to the population size covered, limited information appears to be published in relation to the current level of recruitment among the different professional groups and the present level of unfilled posts. However there appears to a general consensus that recruitment of Allied Health Professionals – notably speech and language therapists - is difficult in Northern Ireland at present. This may be because they are able to work in a wide range of settings and learning disabilities may not be presented as an attractive career pathway.

Similarly difficulties appear to exist in recruiting staff to clinical psychology posts.

No figures have been published on the number of nurses entering learning disability nurse training, however there have been some suggestions that applications have been reducing and by tradition there have always been fewer recruits to this branch of the profession. Students may opt to undertake their training in the other three branches in the belief that it provides more opportunities to develop a career. Furthermore since 2001, learning disability nurse training has only been available at Queens University in Belfast which may be a disincentive for people from other areas of Northern Ireland.

No clear and concise information is currently compiled at a Northern Ireland level on the difficulties being experienced in recruiting qualified and unqualified staff into statutory or independent learning disability services and the factors thought to be contributing to these difficulties. The absence of such information is a major gap in our knowledge, which reduces the opportunities to develop and implement comprehensive strategies to ensure the availability of staff for the required workforce across Northern Ireland.

Broad factors contributing to staff leaving learning disability services

The most comprehensive review of literature relating to the retention of staff within community based services for people who a learning disability within the United Kingdom and the USA identified eight key factors that have been consistently reported as contributing to staff turnover in learning disability services (Hatton et al., 2001). These factors were:

- Characteristics of staff (younger people, those with higher education and those on shorter contracts moved on more frequently)
- Lower income / less satisfaction with income
- Mismatch between expectations and actual job
- Lack of commitment to the organisation or general type of work
- Lack of support from other staff
- The availability of alternative employment
- High job stress
- Low job satisfaction

These factors tend to mirror the findings in non-learning disability services. However this list is not in rank order, nor is it clear how these factors interact with each other. The extent to which each factor contributes to an individual's decision to leave their job will also be influenced by personal circumstances, including family commitments and their longer term plans.

Furthermore, several of the factors identified in the literature as influencing retention of staff may well be particularly relevant in relation to staff recruitment. If the evidence shows that younger people, those on short term contracts or temporary positions, or lower incomes are more likely to leave their post equally these factors may contribute to reluctance in seeking employment in learning disability services.

Many unqualified direct care posts are short term and provide an income that may not be considered satisfactory to young people. This may be especially so if there is availability of alternative employment such as retail outlets, or office based positions that are viewed as having better working conditions (for instance, less shift work, more support, less isolated working, a reduced risk of aggression).

Relevant factors in day-to-day work

In seeking to identify the factors in day-to-day work settings that directly and indirectly contributed to the broader categories listed above, Hatton et al. (1999; 2001) collected data from 450 staff across a range of community based services including community residential services, community learning disability teams, a village community and educational provision. The majority of people in the sample were reported as unqualified staff (59%) reflecting the large percentage of people in this category within services. But the research also involved managers, qualified nursing and social work staff as well as speech and language therapists, psychologists and teachers.

This project identified five broad areas that influenced the retention of staff and the directly contributing factors on each (Table 1) and Appendix 2.1 gives for further details.

Table 1: Broad areas and directly contributing factors that were found to influence to the retention of staff in learning disability services (Hatton et al., 1999; 2001).

Broad areas identified	Directly contributing factors
General distress	Wishful thinking (rather than problem solving approach) Work – home conflict
Job Strain	Wishful thinking (rather than problem solving approach) Stress linked to lack of staff support Alienative communication Role ambiguity Stress linked to lower job status Longer contracted hours
Work satisfaction	Less stress linked to low status job Support form supervisors Greater influence over work Less alienative communication Support form colleagues Older staff age
Intention to leave	Less job satisfaction Higher job strain Younger age Easier subjective labour conditions
Job search behaviour	Less work satisfaction Higher job strain Easier subjective labour conditions

A wide range of factors beyond individual staff characteristics contributed to the retention of staff. It was also clear that among other things the support provided by colleagues and managers, role clarity (including the need for training), the ability to problem solve and perceived status and control over ones job contribute to general distress and job strain among staff. These factors are interlinked with work satisfaction, which in turn can influence intention to leave and job-search behaviour.

These findings are similar to those identified as contributing to the job satisfaction of Community Nurses for people with a learning disability in Northern Ireland and Wales (Parahoo & Barr, 1996; Broader, 2002; Barr, 2004a). In these three surveys nurses were increasingly frustrated that meetings, the need for reports and computer records distracted them from their direct work with clients.

Factors related to direct care experience and career planning

The findings of Hatton et al., (1999; 2001) have been added to by a number of research studies that have investigated the experience of direct care staff in working with people with a learning disability. In particular, attention has been given to the experience of staff who work with people with a learning disability who present challenging behaviour and / or self injurious behaviour (Gentry et al., 2001; Bell & Espie, 2002; Hastings & Brown, 2002; Hill & Dagnan, 2002; Wanless & Jahoda, 2002), within forensic services

(Taylor et al., 2003) and around the area of sexuality among people with a learning disability (McConkey & Ryan, 2001).

These studies have highlighted the perceived lack of preparation, low levels of confidence and vulnerability to negative emotional reactions (and resultant stress) of staff towards people with people with a learning disability.

Reduced confidence and lack of preparation of staff can make them vulnerable to experiencing negative emotions and attributing the presence of challenging behaviour to the person with a learning disability. However as these studies did not have comparison groups it is not possible to say that the difficulties experienced in working with people with challenging behaviour were more or less than those dealing with other people, for instance with clients who have life-limiting conditions or complex health needs.

However it has been reported that working with people who present with self-injurious behaviour increases negative emotions in comparison to people who have challenging behaviour which is stereotypical or repetitive (but not self injuring) in nature (Hastings & Brown, 2002). Wanless and Jahoda (2002) highlighted the increased risk of staff experiencing negative emotions and making negative attributions to people with a learning disability, particularly those who presented with physical rather than other forms of aggression.

There is also some evidence that the work setting people are in and their professional training may also impact on their reaction and perceived confidence. Hastings and Brown (2001) reported that staff in a special school reported low levels of behavioural knowledge and low self-efficacy which the researchers argued increased the vulnerability of school staff to experiencing negative emotions and attributions leading to less effective reactions to people who presented behaviour that was considered challenging.

In a study within Northern Ireland involving staff from day care, community residential accommodation and special schools, McConkey and Ryan (2001) reported that staff in residential services reported being more confident in dealing with sexuality issues and inappropriate sexual behaviour in comparison to staff within day services. They also reported that age, qualifications, previous experience and religious affiliations impacted on reported reaction towards the sexuality of people with a learning disability (Ryan and McConkey, 2001). For example staff who were regular church attenders held more conservative attitudes towards sexual expression than non-church goers.

These studies demonstrate the influence of both the work setting and the nature of clients' needs they are trying to meet. They highlight the need for tailored training and education of staff and supervision that supports them in practical ways to work more effectively with the particular issues they encounter within their work environment when supporting people with a learning disability.

Finally, the potential of poor or limited career advice has been raised as a factor that could impact on both the recruitment and retention of staff in learning disability services. Marsland (2001) in a Department of Health study of 225 learning disability nurses found that a substantial proportion did not receive guidance about many aspects of their career planning, with only 60-63% receiving information on jobs for which their skills may be particularly suited, and on the career pathways for people with a learning disability nursing qualification in the NHS or outside the NHS.

Just over half (55%) had received information or guidance on developing a career in clinical practice and the majority did not receive information on undertaking additional

Table 2: Key strategies identified that seek to promote retention of staff in learning disability services.

(Taken from: Hatton et al., 1999; 2001; Gentry et al., 2001; Marsland, 2001; McConkey & Ryan, 2001; Smith et al., 2002; Taylor et al. 2003).

- **Provision of adequate induction**
  - To provide staff with realistic expectations
  - To clarify role of staff
  - To highlight and promote commitment to values of the service
- **Development of more flexible working practices**
  - To attract more older people (who appear less likely to move on)
  - To reduce the degree of work – home conflict
- **Consider pay and conditions**
  - Provide pay and conditions that reflect value for the knowledge and skills necessary to undertake the role
  - Review pay and conditions in light of availability of alternative employment
  - Consider how to provide develop a career pathway for staff providing the opportunities for progression in services
- **Provide training for staff**
  - Provide a programme of on going training for staff to develop their knowledge, skills and confidence
  - Incorporate into training difficulties identified by staff in supporting people with a learning disability
  - Training for staff in relation to practical tasks they will completed
  - Focus on problem solving skills development (to wishful thinking)
- **Take action to reduce job strain**
  - Make staff roles clear
  - Streamline bureaucratic procedures whilst maintaining quality
  - Provide effective feedback on staff work and supervision opportunities / team meetings for all staff, and particularly those working alone
  - Give attention to the length of shifts and how this relates to other commitments staff members may have
- **Seek to improve job satisfaction**
  - Provide effective feedback on staff work and supervision opportunities / team meetings for all staff, and particularly those working alone
  - Provide opportunities for on going training and information about career development
  - Facilitate staff having greater control of their how they do their job were this is possible and decisions made by the organisation
  - As an organisation demonstrate a positive commitment to staff

clinical courses, applying for such courses, or developing careers in management in the NHS, nurses education or nursing research. Marsland (2001) concluded that given the changing nature of services for people with a learning disability, career guidance and related information was an important aspect of career development and that its limited availability could impact negatively on recruitment and retention of nursing staff in learning disability services. No similar studies were identified for staff within other professionals working with people with a learning disability.

Another neglected area has been the skill-mix of staff within services, for example the ratio of trained and experienced staff to those with no training and little previous experience. With increased pressure on service budgets, increasing numbers of untrained staff are now being employed.

Recommendations for change

A number of authors have made recommendations for increasing the recruitment and retention of staff. These are summarised in Table 2 overleaf and apply to staff at all levels and across roles.

These highlight the need to provide an adequate process of induction for staff new to services, be that new to working with people who have a learning disability, new to an organisation or a specific type of service.

This period of induction should be built upon by on-going training for staff that provides the necessary knowledge and skills (including problem-solving and coping skills) to undertake their role. A survey of 33 provider agencies in Northern Ireland (Bogues, 1999) employing an estimated 2,300 staff, found that 66% of staff held no professional or vocational qualification. The demand for training was most marked in the areas of challenging behaviour and sexuality/personal relationships and also for management development training. However the most commonly reported barrier to accessing training was releasing staff from duties to attend training events.

Action also needs to be taken to provide more flexible working practices and pay and conditions that value the contribution made by staff.

Finally, steps should be taken to reduce job strain and improve job satisfaction by taking action to counter the impact of the direct and indirect effects that contribute to this (see also Appendix 2.1).

There is a need for more research to focus on staffing issues and in particular the impact that different organisational cultures at both a macro- and micro-level can have on staff morale and retention and the implications this has for the quality of service offered and the outcomes achieved for the persons using the service.

Conclusions

Although personal characteristics of staff may impact on recruitment and retention, the research clearly demonstrates that the majority of impact arises from service and organisational based factors. This is a hopeful feature as it provides a direction for developments and identifies practical actions that may be taken, but will also require services to become more focused on supporting staff, less hierarchical on their structures and more focused on learning new ways of developing person-centred services (Ilkes, 2003). Issues relating to staff training needs to be addressed urgently.

Section 4: Staffing implications arising from the changing nature of services

New styles of community-based services mean that staff work in smaller teams or alone for longer periods of time compared to previous service structures. They are also taking on a wider range of roles. These changes have implications for staffing; in particular, four areas are identified as requiring further consideration.

- The employment of nurses in services in which they were not traditionally employed (e.g. nurses for people with a learning disability in special schools).
- Professionals moving into new roles, as a development or distinction from their previous professional role (e.g. staff work in specific behaviour support or mental health services. Teachers or social workers taking on the role of transition co-ordinators and therapists working as early intervention specialists).
- Restructuring of community teams with a growing variation in team configurations that differ across health and social services trusts and boards (e.g. development of children's disability teams, wider disability teams, and specific behaviour support services).
- New services emerging outside of learning disability services but now working with people with a learning disability (e.g. community children's services, health visitors and school nurses with specific roles for children with a learning disability).

However an evidence-base is often lacking to under-pin the rationale for these changes and often little evaluation is undertaken of existing and new staff roles to ascertain the impact of the change. Hence this section is largely descriptive of the main changes than are most evident.

The employment of nurses in schools and day centres

The changing demography of people with a learning disability, in particular the increasing number of children and young adults with complex health needs has resulted in the need for additional support within special schools (as all children are entitled to an education). This has resulted in much discussion as to how best the needs of these children should be met and similar discussions have taken place in relation to the additional support needed in responding to the complex health needs of people with a learning disability in day services. The difficulties arise around the need to provide complex physical care (e.g. enteral feeding, medication via PEG tubes, suction) and without this support people will not be able to attend school or day services. However some debate has existed around who has the responsibility to provide such services, is it health and social services, education, or both? (McConkey and Kelly, 2001; Marshall and Foster, 2002).

Since the provision of education became the responsibility of Education and Library Boards in 1997, nurses have not traditionally been employed in special schools as 'nurses', although some people with nursing qualifications worked in other roles such as classroom assistants. A survey of all special schools in Northern Ireland found that different types of nurses were involved with special schools although few were based there full-time (McConkey & Kelly, 2001). This study identified inconsistency in the perceived level of input into schools between School Principal and Directors of Nursing Services within the Local Health and Social Services Trusts. The authors highlighted the risk of this leading to plans being developed on the basis of mistaken assumptions about the level of contact and the role of nurses in schools and recommended further research to clarify the situation across Northern Ireland.

More schools in Northern Ireland now appear to have nurses on-site during school time and some preliminary evaluation of their role has found the presence of nurses to be well received by education staff and that nurses completed a wide range of tasks in relation to physical care of children, staff training and health planning (Moore et al., 2003).

As in special schools, people with nursing qualifications have often been employed in day centres in a number of roles, usually as day care workers or senior day care workers, but not as nurses. However community nurses were required to visit the centres to undertake clinical tasks and even with careful forward planning this restricted the activities that the person with a learning disability could participate in as they had to be in the day centres when the community nurse attended.

In the past few years nurses have been appointed as nurses within day centres of at least one HSS Trust in Northern Ireland, although no published evaluation on the impact of this is available.

In summary, the present arrangements for providing support to meet the physical health needs of people with a learning disability in special schools and day centres across Northern Ireland are highly variable and inconsistent. In some areas children and adults with complex health needs are well supported and can avail of services provided, whereas in other areas people continue to have their access to education and day services restricted due to lack of appropriate support within services.

Professionals moving into new roles

There is a trend towards professionals undertaking more specialised functions within services, for example, the appointment of epilepsy nurses within learning disability services. Community nurses in learning disability are also obtaining a qualification in children's nursing so that they can specialise in the care of children with complex needs. The development of behaviour support services will depend on professionals from a range of disciplines taking on a new and more specific role.

The pattern of service developments elsewhere in the United Kingdom suggests that such developments will continue and may extend to staff with specific roles in relation to mental health, health facilitation and acute liaison nurse posts.

These service developments are predicated on the identified needs of people with a learning disability, however they take professionals into new areas of work, new methods of working and new structures for which there maybe no appropriate training or peer support.

They will also place new demands on these professionals in terms of leadership roles, consultancy skills, lobbying and advocacy.

Restructuring of community teams

The concept of a team of professionals – usually nurses, social workers, psychologists and therapists – serving people living in community settings has been a feature of learning disability services in the UK since the 1970s. However the form and functions of these teams varies widely and comparatively little research has been undertaken into their effectiveness despite the sizeable costs involved.

The structure of community teams providing service to people with a learning disability is changing across Northern Ireland. Many Trusts have moved away from the formally structured Community Learning Disability Team that provided services to children and adults with a learning disability. A number of different team structures now exist, including Children's Disability Teams (some are interdisciplinary, other social workers only), Adult Disability Teams supporting people with all disabilities (but with some team members only supporting people with a learning disability), separate Community Nursing Teams and Community Social Work teams for people with a learning disability (with varying degrees of collaborative working).

Whilst considerable literature exists about the requirements for effective team work (Sines & Barr, 1998, Weinstein, 1998), at present there is no clear evidence on the impact of different team structures in support of people with a learning disability, nor conclusive evidence on the most effective team structure within community learning disability services. However a major project is underway lead by Dr Eamonn Slevin (University of Ulster) on the impact of team structures in preventing admission of people with a learning disability to specialist hospitals and supporting them on discharge.

New services emerging outside of learning disability service

Developments occurring within other services are also impacting on the role of some staff within learning disability services. For instance the emerging development of Community Children's Nursing services across Northern Ireland has resulted in staff within these services now providing services to some children previously supported by community nurses for people with a learning disability. In addition, the changing role of Health Visitors and School Nurses is likely to impact on the existing role of some staff within Community Learning Disability Teams.

These developments in 'mainstream' services are welcome and they provide additional support options of people with a learning disability and their families. However, these developments can take place in a disjointed manner with little consultation between services. Two particular areas for attention are the sharing of information between services and the development of coherent arrangements for co-working and transition between services.

Implications for staffing

As new services develop and people take on new or revised roles it is important that the factors identified in Table 2 are built into services in order to promote an effective working environment that retains staff involved. This is particularly important in the development phase of new roles and services when considerable investment has been made in staff induction and training, and the possibility of replacing a member of staff who leaves a service could be difficult due to the innovative nature of their role.

It is also necessary to consider the impact that staff moving from existing services within Community Learning Disability Teams will have on the capacity of the team to fulfil its role if several experienced staff move into new services. Hence plans need to be in place to recruit staff into the posts left vacant by such developments. Such plans also need to consider the post qualification training necessary for people who may come into the vacant posts. All new services must be planned and developed with a view to how they fit into existing structures, rather than become parallel or disjointed services.

Furthermore as services supporting people with a learning disability are now emerging separately within learning disability and mainstream services specific attention needs to be given to collaborative planning and working arrangements between services who have traditionally planned separately if the maximum gains are to be made for people with a learning disability and their families. Such collaborative arrangements should provide clear guidance on boundaries of responsibilities of teams, clarify the roles of staff, detail arrangements for providing appropriate clinical and managerial supervision and provide an equitable structure for career progression of staff entering new / revised roles or team structures.

Conclusions

As services shift away from an exclusively specialist orientation towards greater engagement with mainstream services, increased attention needs to be paid to redefining staff roles and relationships within and across services. This is often done on an ad hoc rather than planned basis and often after the new changes have been implemented rather than as part of the necessary planning for them.

Section 5: Staff in mainstream services working with people who have a learning disability.

Despite the fact that 'inclusion' has been a policy aim in Northern Ireland since 1995 (DHSS, 1995), people with a learning disability continue to be encounter persistent difficulties in gaining equity of access to services as noted earlier. In particular, difficulties have been reported in accessing primary care and acute general hospital services within Northern Ireland (Barr et al., 1999; Barr, 2004b) and in other parts of the United Kingdom (Thornton, 1999; Giraud-Saunders et al., 2003; NPSA, 2004). To a large extent these stem from the attitudes of staff in these sectors.

Staff in Primary Care Services

The views of professionals in primary care towards people with a learning disability and their limited skills in communication have been identified as factors influencing the service provided to people with a learning disability (Singh, 1997; Band, 1998). In a survey of General Practitioners in the WHSSB area, Finlay (2002) reported that 48% of General Practitioners and 49% of nurses did not feel they had adequate training to work with people with a learning disability, while 20% of General Practitioners and 17% of nurses felt that had. The remaining 32% of General Practitioners and nurses were uncertain about their degree of preparation. They reported limited preparation and uncertainty about how to work with people who have a learning disability. These findings are consistent with those reported elsewhere in the United Kingdom (Kerr et al., 1996; Bond et al., 1997; Stein, 2000; Gill et al., 2002).

Even so General Practitioners have generally positive attitudes towards people with a learning disability and whilst accepting of their responsibility to provide general medical services for people with a learning disability, they believe health screening should be provided within specialist services (Gill et al. 2002). In a survey of GPs within Down Lisburn Trust although the majority of General Practitioners felt health screening would be helpful for people with a learning disability, three quarters of those responding felt these would be better provided within specialist services. However after dealing with referrals from a contact with a health screening service provided by Community Nursing Learning Disability services, General Practitioners reported being more favourable to undertaking health screening themselves (McConkey et al. 2002). This would support the importance of collaborative working between specialist and primary care services and demonstrates that such collaboration could lead to improve equity of access to health screening in primary care settings.

Most surveys have taken place with nurses and General Practitioners with little information on the views of the wide range of other professionals. However research evidence also shows that people with a learning disability often do not avail of other health services within community settings (e.g. dentist, optician, audiologist, speech and language therapist, dietician) (Band, 1998). Given the reported impact and views of General Practitioners and nurses on the availability and access to services, further research is needed to establish the views of other professionals and their impact.

Staff in Acute General Hospitals

It is recognised that nurses within acute hospitals also report experiencing difficulties in working with people with a learning disability. Indeed, the National Patient Safety Agency has recently highlighted the seriousness of this situation and after a comprehensive process of consultation within England have identified the care of people with a learning disability in general hospitals as one of their top priority issues (NPSA, 2004).

Studies consistently report a limited confidence and uncertainty about what to do in working with people with a learning disability both in Northern Ireland (Slevin & Sines, 1996; McConkey & Truesdale, 2000; Barr 2004b) and elsewhere in the United Kingdom (NPSA, 2004). Nurses often reported limited knowledge, skills and experience towards caring for people with a learning disability. Likewise a study undertaken in Northern Ireland which included 167 student therapists (mainly physiotherapists and occupational therapists) reported that they had significantly less confidence and felt more unprepared to work with people with a learning disability than people with physical disabilities (McConkey & Truesdale, 2000).

Using focus groups with staff from general hospitals in one area in England, Cumella and Martin (2000) identified four key areas of difficulty, namely poor information on admission, limited staff training in the needs of people with a learning disability, risk to other patients (actual or perceived) and difficulties in obtaining consent that at times made staff wary of undertaking interventions. Nursing staff in acute general hospitals highlighted their lack of preparation to work with people with a learning disability during their pre and post qualification education.

Evidence is available from within Northern Ireland (Marshall et al, 2001; McConkey et al, 2003) and elsewhere in the United Kingdom (Jones & Kerr, 1997; Martin et al., 1997) to show that when primary care and specialist learning disability staff work collaboratively, the health status of people with a learning disability can be improved. Equally, collaboration between acute general hospital services and learning disability service has resulted in the development of several Acute Liaison Nurses within the England and Scotland. At present no similar posts exist with Northern Ireland. These nurses have a role in providing training for staff as well as contributing to policy development, research and service development. A network of Acute Liaison Nurses known as 'Access to Acute' now exists across the United Kingdom. These projects have been evaluated very successfully and have taken considerable steps towards achieving equity of access to healthcare (see www.fons.org/networks/nnldn/a2a).

In addition Health Facilitators have been appointed with a specific role in working between learning disability and primary care services within services in England, Scotland and Wales, in effect providing the co-ordinating link (Department of Health, 2001). However, at present there is no equivalent to Heath facilitators within Northern Ireland.

In order to further the objective of inclusion, the perceptions and needs of staff within non-learning disability services must be considered and action taken to provide the support needed for inclusion to become an accepted aim of these services. To be effective collaborative working needs must go beyond providing information to primary care and acute general hospitals services about what needs to be done, it needs to include practical support, training and sharing of information. Further education and opportunities to develop skills in working with people with a learning disability are required and should emphasise the need for skills in communication, legal and ethical issues (particularly informed consent and restraint), working with families, working with people who present challenging behaviour and the resources available to support people with a learning disability (Band, 1998; Barr, 2004; NPSA, 2004).

Such collaborative arrangements should be evaluated against the degree they result in an increased capacity among mainstream services to support people with a learning disability and must go beyond families of people with a learning disability or staff in learning disability services providing parallel services. It can also be expected that such developments as those noted above in relation to primary and acute care services will also be necessary for staff in wide range of other services, the key point being that inclusion will never be achieved if the knowledge, skills and values are not in place within mainstream services.

Conclusions

In future the focus on staffing for learning disability services will need to embrace mainstream provision. In particular means will need to be found for sharing the knowledge and expertise that has accumulated within specialist services for meeting the particular needs of people with a learning disability. However this process has begun and initial results seem promising.

Concluding Comments

The impact of organisational arrangements and working practices can have a major impact on staff stress, work satisfaction, staff turnover and most importantly directly and indirectly on the people with a learning disability and their families who use services. As new services become increasingly built around more dispersed smaller units with the consequent need for increased numbers of staff, careful thought has to be given to steps to increase the recruitment and retention of staff. A career in working with people with a learning disability needs further publicity; jobs in learning disability services should be presented as positive and desirable position and publicity should highlight the benefits of undertaking such work.

There is also the need to move towards more joined-up planning with mainstream services in order that their service developments and those of learning disability services, provide coherent rather than fragmented or competitive services. This level of planning is also necessary within learning disability services as new team structures, staff roles and supervision arrangements are developing, which in turn has major impacts on the work on existing professionals and on community learning disability teams.

There is also a need to invest in the development of the necessary knowledge, skills and values in staff within specialist and mainstream services. This will require longer term planning to have adequate numbers of trained staff available in the future. Above all any changes to staffing and services should be evaluated against the increase in quality of care and support they provide to people with a learning disability, their families and carers. To date, this evidence base is sadly lacking.

References

Band, R. (1998) *The NHS - Health for all? People with learning disabilities and healthcare.* London. Royal Society for Mentally Handicapped Children and Adults.

Barr, O., Gilgunn, J., Kane, T., & Moore, G. (1999) Health screening for people with learning disabilities by a community learning disability service in Northern Ireland. *Journal of Advanced Nursing* 29, 1482-91.

Barr, O. (2004a – in preparation) *The working practices of community nurses for people with learning disabilities and the people who use their services: Changes in Northern Ireland between 1992 and 2003.* A report prepared for the NICNLDPDF.

Barr, O. (2004b) *Promoting Access*: The experience of children and adults with learning disabilities and their families / carers who had contact with acute general hospitals in the WHSSB Area and the views of the nurses in these hospitals. A reported prepared for the WHSSB.

Bogues, S. (1999) *Meeting the training and development challenge for staff in services for people with learning disabilities.* Belfast: ARC (NI).

Bell, D., & Espie, C. (2002) A preliminary investigation into job satisfaction, and staff emotions and attitudes in a unit for men with learning disabilities and serious challenging behaviour. *British Journal of Learning Disabilities.* 30, 19-27.

Bond, L., Kerr, M., Dunstan, F., Thapar, A. (1997) Attitudes of general practitioners towards health care for people with intellectual disability and the factors underlying these attitudes. *Journal of Intellectual Disability Research,* 41, 391-400.

Broader, J. (2002) The perceptions of experienced community learning disability nurses of their roles an ways of working: an exploratory study. *Journal of Learning Disabilities,* 6, 281-296.

Carers UK (2002a) *Without Us...? Calculating the value of carers' support.* London, Carers UK

Carers UK (2002b) *Adding Value: Carers as drivers of social change.* London, Carers UK.

Cumella, S. & Martin, D. (2000) *Secondary Healthcare for People with a Learning Disability. A report completed for the Department of Health.* (available at www.fons.org/networks/nnldn/a2a)

David-Smith, J. (1998) *The 1997 national survey of volunteering.* London: Institute for Volunteering Research.

Department of Health (2001) *Valuing People: A new strategy for the 21st Century.* London: Department of Health.

Finlay, L (2002) *Primary Concern: people with a learning disability.* WHSSB, Londonderry.

Gentry, M., Iceton, J. & Milne, D. (2001) Managing challenging behaviour in the community: methods and results of interactive staff training. *Health and Social Care in the Community*, 9, 143-150.

Gill, F., Stenfert Kroese, B. & Rose, J. (2002) General Practitioners' attitudes to patients who have a learning disabilities. *Psychological Medicine*, 37, 1445-1455.

Giraud-Saunders, A., Gregory, M., Poxton, R., Smith, C & Towell, D. (2003) *Valuing health for all: an action guide.* London. Kings Fund.

Hastings, R. & Brown, T. (2002) Behavioural knowledge, causal beliefs and self efficacy as predictors of special educators' emotional reactions to challenging behaviours. *Journal of Intellectual Disability Research*, 46, 144-150.

Hatton, C., Emerson, E., Rivers, M., Mason, H., Swarbrick, R. et al. (1999) Factors associated with staff stress and work satisfaction in services for people with intellectual disability. *Journal of Intellectual Disability Research*, 43, 253-267.

Hatton, C., Emerson, E., Rivers, M., Mason, H., Swarbrick, R. et al. (2001) Factors associated with intended staff turnover and job search behaviour in services for people with intellectual disability. *Journal of Intellectual Disability Research*, 45, 258-270.

Hatton, C., Emerson, E., Robertson, J., Henderson, D. & Cooper, J. (1996) Factors associated with staff support and resident lifestyle in services for people with multiple disabilities: a path analytic approach. *Journal of Intellectual Disability Research*, 40, 466-477.

Hill, C. & Dagnan, D. (2002) Helping attributions, emotions and coping styles in response to people with learning disabilities and challenging behaviour. *Journal of Learning Disabilities*, 6, 363-372.

Holloway, T. and Mawhinney, S. (2002) *Providing support, reducing exclusion: the extent, nature and value of volunteer befriending in Northern Ireland*. Belfast: Praxis care Group.

Jones, R.G. & Kerr, M.P. (1997). A randomised control trial of an opportunistic health screening tool for people with intellectual disability. *Journal of Intellectual Disability Research*, 41, 409-415.

Kerr, M., Dunstan, F. & Thapar, A. (1996). Attitudes of general practitioners to people with a learning disability. *British Journal of General Practice*, 46, 92-94.

Larson, S.A. and Lakin, K.C. (1999) Longitudinal study of recruitment and retention in small community homes supporting persons with developmental disabilities. *Mental Retardation*, 37, 267-280.

McConkey, R. (2004) *Pressures, Possibilities and Proposals: Northern Ireland Review of Day Services for People with Learning Disabilities,* Belfast: EHSSB.

McConkey, R., Barr, O., Fleming, P. & Milligan, V. (2003). *Evaluation of Challenge 2000: Health Screening and Health Promotion Service provided by North & West Locality Consortium (Belfast) to people with learning disabilities. (Clifton Street Surgery, Belfast and EHSSB).*

McConkey, R. & Bhurgri, S. (2003) Children with autism attending preschool facilities: The experiences and perceptions of staff. *Early Child Development and Care*, 173, 443-452

McConkey, R & Kelly, M (2001) Nursing inputs to special schools in N. Ireland. *International Journal of Nursing Studies*, 38:395-403.

McConkey, R., McConaghie, J., Roberts. P. & King, D. (2003) Characteristics of people providing family placements to adult persons with intellectual disabilities. Jordanstown: University of Ulster.

McConkey, R., Moore, G., & Marshall, D. (2002) 'Changes in the attitudes of GP's to the health screening of people with learning disabilities' *Journal of Learning Disabilities*, 6(4): 373-384.

McConkey, R. & Ryan, D. (2001) Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability. *Journal of Intellectual Disability Research*, 45, 83-87.

McConkey, R. & Truesdale, M. (2000) Reactions of nurses and therapists in mainstream health services to contact with people who have learning disabilities. *Journal of Advanced Nursing*. 32, 158-163

McConnell, R. & McConnell, P. (2003) Perceptions of the Special Olympics Experience. Jordanstown: University of Ulster.

Marshall, D. & Foster, I. (2002). Providing a healthcare input to children in special schools. *British Journal of Nursing*, 11, 28-35.

Marshall, D., McConkey, R., & Moore, G. (2000) *Healthcheck 2000 Evaluation report*. Lisburn, Down Lisburn Trust.

Marsland, L. (2001) Career guidance received by students qualifying as learning disability nurses. *Journal of Learning Disabilities*, 5, 353-368.

Moore, G., McConkey, R & Duffy, M (2003) The role of the school nurse in special schools for pupils with severe learning difficulties. *International Journal of Nursing Studies*, 40, 771-779.

National Patient Safety Agency (2004) *Understanding the patient safety issues for people with learning disabilities*. NPSA, London.

Parahoo. K. & Barr, O. (1996) Community mental handicap nursing services in Northern Ireland: a profile of clients and selected working practices. *Journal of Clinical Nursing*, 5, 221-228.

Rose, J. (1999) Stress and residential staff who work with people who have an intellectual disability: a factor analytic study. *Journal of Intellectual Disability Research*, 43(4):268-278.

Ryan, D. & McConkey, R. (2000) Staff attitudes to sexuality and people with intellectual disabilities. *Irish Journal of Psychology, 21, 88-97*

Seager, M., Bell, G. & O'Brien, G. (2000) Readmissions to learning disability hospitals: a study of failed discharge due to physical health problems, relapsing mental illness and severe behavioural problems. *Journal of Learning Disabilities,* 4, 321-323.

Sines, D. & Barr, O. (1998) Professions in Teams. In Thompson, T. & Mathias, P. (Eds.) *Standards and Learning Disability 2nd Edition.* Bailliere Tindall, London, pp343-363.

Singh, P. (1997) *Prescription for change.* Royal Society for Mentally Handicapped Children and Adults, London.

Slevin, E. & Sines, D. (1996) 'Attitudes of nurses in a general hospital towards people with learning disabilities: influence of contact of graduate and non-graduate status. A comparative study', *Journal of Advanced Nursing,* 24, 1116-1126.

Smith, C., Felce, D., Jones, E. & Lowe, K. (2002) Responsiveness to staff support: evaluating the impact of individual characteristics on the effectiveness of active support training using a conditional probability approach. *Journal of Intellectual Disability Research*, 46, 594-6-4.

Stein, K. (2000). Caring for people with learning disability: a survey of general practitioners' attitudes in Southampton and South-West Hampshire. *British Journal of Learning Disabilities*, 28, 9-15.

Taggart, L.& McConkey, R. (2001) Working practices employed within and across hospital services and community service provision for adults with an intellectual disability and additional needs. *Journal of Learning Disabilities,* 5, 175-190.

Taylor, J., Keddie, T. & Lee, S. (2003) Working with sex offenders with intellectual disability: evaluation of an introductory workshop for direct care staff. *Journal of Intellectual Disability Research*, 47, 203-209.

Thompson, B., Taylor, H. & McConkey, R. (2000) Promoting inclusive play and leisure opportunities for children with disabilities. *Child Care in Practice*. 6, 108-123

Volunteer Development Agency (2001) Volunteering in Northern Ireland. Belfast: Volunteer Development Agency.

Wanless, L. & Jahoda, A. (2002) Responses of staff towards people with mild to moderate intellectual disability who behave aggressively: a cognitive emotional analysis. *Journal of Intellectual Disability Research*, 46, 507-516.

Weinstein, J. (1998) Professions and their interrelationships. In *Standards and Learning Disability 2nd Edition.* Thompson, T. & Mathias, P. (Eds.) Bailliere Tindall, London, pp323-342.

Appendix 2.1: Factors influencing the retention of staff.

Hatton et al., (1999; 2001) identified the broad areas that influenced retention of staff in learning disability services and for each area the direct and indirect contributing factors. These were as follows:

Broad Areas identified	**Directly contributing factors**	**Indirectly contributing factors**
General distress	Wishful thinking	Lack of staff support Bureaucracy
	Work – home conflict	Work home conflict
	Role ambiguity	Younger staff age Receiving less training as part of job
Job Strain	Wishful thinking	Lack of staff support Bureaucracy
	Stress linked to lack of staff support	Less support form supervisors and colleagues Greater role conflict Greater person –organisation mismatch concerning tolerance and being orientated towards staff
	Alienative communication	Greater role conflict Greater stress linked to low status job Greater person –organisation mismatch concerning tolerance and being orientated towards staff Less orientation towards working in services for people with a learning disability
	Role ambiguity	Younger staff age Receiving less training as part of job
	Stress linked to lower job status	Greater role conflict less job control Greater person –organisation mismatch concerning rewards for staff
	Longer contracted hours	Being male Not having dependents
Work satisfaction	Less stress linked to low status job	Less role conflict Greater job control Greater person –organisation fit concerning rewards for staff
	Support form supervisors	Receiving more supervisor feedback
	Greater influence over Work	More staff meetings Doing fewer domestic tasks

		Receiving more supervisor feedback Harder subjective labour conditions
	Less alienative communication	Greater person – organisation fit concerning tolerance and being orientated towards staff Less role conflict Less stress linked to low status job Greater orientation to working in community based services
	Support form colleagues	Receiving more supervisor feedback
	Older staff age	
Intention to leave	Less job satisfaction	Low levels of support from supervisors and colleagues Low influence over work decisions High levels of stress from low status job High level of alienative communication Younger staff age
	Higher job strain	High use of wishful thinking High stress associated with lack of staff support and bureaucracy High role ambiguity High level of alienative communication Working longer contracted hours
	Younger age	
	Easier subjective labour conditions	Less community employment orientation Younger staff age
Job search Behaviour	Less work satisfaction	Low levels of support from supervisors and colleagues Low influence over work decisions High levels of stress from low status job High level of alienative communication
	Higher job strain	High role ambiguity High level of alienative commitment (feeling trapped in a poor organisation) Working longer contracted hours
	Easier subjective labour orientation	Less community employment conditions

Chapter 3:
Accommodation and Support Needs of People with a Learning Disability

Overview

By definition people with a learning disability need to be 'looked after'. Throughout most of the last century this was mainly the responsibility of the family. The only alternative was to be cared for in long-stay hospitals. In December 1962, over 1,800 persons were resident as 'special care' patients in Hospitals in Northern Ireland (Scally and McKay, 1964).

From 1970s onwards, new forms of accommodation and support options began to become available especially for people who were resettled from long-stay hospitals. This included the provision of community-based hostels, residential care and nursing homes, group homes and latterly supported living arrangements located in ordinary housing.

In 2003 around 450 persons now live in three long-stay Hospitals and nearly 2,000 are in some other form of accommodation options.

This chapter is structured into five main sections.

Section 1 gives an overview of where Northern Irish people with a learning disability are living in 2003 and draws comparisons with Great Britain and the Republic of Ireland.

Section 2 summarises research findings relating to people in long-stay hospitals is presented.

Section 3 focuses on existing residential provision and supported living schemes.

Section 4 examines the future accommodation needs of people living with family carers and the options favoured by people with a learning disability and family carers.

Section 5 contains a synopsis of the national and international literature relating to key themes that have not been well explored in the Northern Irish context.

Section 1: Where are people living?

Nearly all children (up to 19 years of age) live in family homes either with natural, adoptive or foster parents (McConkey, Spollen and Jamison, 2003).

Accurate figures are not available for all of Northern Ireland but a study in the EHSSB area identified 34 children (aged up to 19 years of age) who were living in some form of residential accommodation with 26 in foster care arrangements. Together these represent 2% of all children known to HSS Trusts in the Board area (McConkey et 1l, 2004).

Figure 1 shows where adult persons are living.

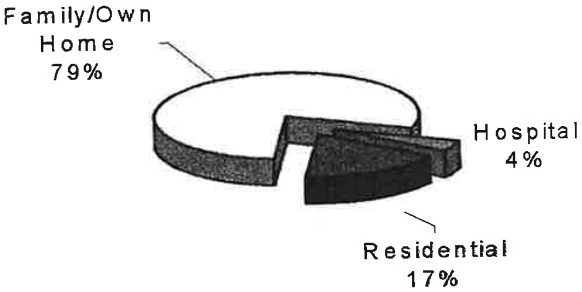

Figure 1: Percentage of adults person in different forms of accommodation in N. Ireland in 2003 (N=7,970)

The bulk of people live with family carers (66%) although a small proportion have their own accommodation (10%) or live with a spouse/partner (3%).

Around 450 are resident in hospitals (mostly learning disability hospitals) and on average will have lived there for 20 years.

Nearly 1900 persons are in some form of residential provision and have lived there for around 8 years on average.

Comparable figures across these three forms of provision for the Republic of Ireland (Health Research Board, 2003) are: Hospitals (4%); Residential services (5 day and 7 day) (39%); Community (57%).

In Great Britain, an estimated 63% of adults live in private households and 37% in some form of residential accommodation. The numbers living in long-stay hospitals are now less than 1% (Kavanagh and Opit, 1999).

This data suggests that over twice as many adult persons are in residential provision in Great Britain and in the Republic of Ireland than in Northern Ireland.

Section 2: People living in long-stay Hospitals

The annual census of Hospital In-patients (DHSSPS) identifies the number of people in the three main learning disability Hospitals in N. Ireland on a specific date. However this data does not distinguish between those patients for whom the hospital is their home and those who are undergoing short-term admissions. Hence in the study undertaken by McConkey, Spollen and Jamison (2003) further information was obtained from Boards and Trusts to clarify this.

In 2003, it was estimated that there were around 440 –470 persons living in learning disabilities hospitals who had no where else to live. The breakdown was as follows:

Muckamore Abbey Hospital	@ 300 persons
Longstone Hospital	@ 115
Stradreagh	@ 40

Around 62% were male and 38% female. The mean age of residents was 49 years, with ages ranging from 9 to 96 years. The over all age profile of the patients is given in Table 1. The EHSSB had a slightly older population, with a mean of 52 years, compared to the other boards where the mean is 47 years (One way Analysis of Variance; F=3.0: p<0.05).

Table 1: The number and percentage of patients by age bands

Age Band	Hospital Census	Census Percent
0-19	18	4.0
20-44	201	44.4
45-64	181	40.0
65-74	29	6.4
75+	24	5.3
Total	453	100

Given a life expectancy of 70 years, this data suggests that over the next ten years a maximum of around one quarter of these patients will die (presuming that there is no replacement of places.) Hence upwards of 350 persons may need to be resettled in the immediate future.

The mean length of time these patients had been in Hospital ranged from 16 years in WHSSB to 24.5 years in SHSSB.

A census of all patients in Longstone Hospitals in 2001 (Slevin et al, 2002) found that of the 135 patients; 14% were rated as having mild learning disabilities; 33% moderate learning disabilities; 41% severe learning disabilities and 12% profound learning disabilities. However people who had been in the Hospital for less than 10 years (N=63) tended to have mild/moderate learning disabilities (78% of this grouping) whereas people who had stayed for greater than 10 years (N=72) tended to have severe/profound disabilities (69%). In addition, 27% of patients were reported to have significant challenging behaviours and 17% significant mental health problems.

This data suggest that the more able and less demanding patients have tended to move out of the Hospitals leaving behind people who have greater needs in terms of service provision.

Delayed discharge

In recent years, Muckamore Abbey Hospital has been reconfigured into resettlement wards and assessment and treatment wards. In May 2001, 172 patients were in the latter wards but 33% were considered by their consultant psychiatrist as having their treatment completed and they were awaiting discharge (McConkey and Marriott, 2001). However there was no available place to which they could be safely discharged. This phenomena of 'blocked beds' has been reported also in Scottish Hospitals (Whoriskey, 2003). The consequence is that a new 'long-stay' population emerges in Hospitals. Of 154 people admitted to Muckamore Abbey Hospital over a two-year period, 17 (11%) were unable to be discharged and of these 11, had been in hospital for greater than a year. The main reasons given for not discharging the patients were: no capacity available in any appropriate care home/supported housing; care planning was in progress; no funding was available and necessary equipment and adaptations were not available (McConkey et al, 2002).

Likewise in Longstone Hospital a total of 19 people had been admitted in the previous five year period and had been there for at least one year; they account for 15% of the present Hospital population (Slevin et al, 2002).

Offending behaviours

Long-stay hospitals have provided another function; namely detaining people with a learning disability who have offended in semi-secure accommodation although those who require to be detained in high security are sent to Carstairs in Scotland. The precise numbers of people are not known.

The needs of people with intellectual disabilities who break the law are generally thought to be better met within health and social services than through the criminal justice system (Murphy and Fernando, 1999). This means it can be very difficult to determine the numbers of people who commit offences as they may not come before the courts or the police may decide not to press charges. Simpson and Hogg (2001) concluded after a systematic review of published studies internationally that "there is no compelling evidence that the prevalence of offending among people with ID is higher than for the wider population" (p.394).

They did however find some evidence to suggest that the relative prevalence of sexual offending (particularly against younger and male children), criminal damage and burglary (but not theft) are higher among people with borderline disabilities. Arson also seems to be more common (Day, 1993). However there is little reliable data on which to base estimates of need for secure/semi-secure accommodation (Fraser, 2002).

An international working party (IASSID, 2000) noted that additional mental health problems, drug and alcohol abuse, and social factors, such as homelessness and unemployment, may increase the risk of offending by a person with an intellectual disability and lead to further social exclusion. Preventive measures would include meaningful employment opportunities, and housing, together with assessment and treatment services, and that should be available to people with intellectual disabilities, including those with mild/borderline disabilities whose need are often ignored in present social cares systems.

Persons who pose an ongoing danger to others may need to be detained against their will. Full legal safeguards need to be in place for recognised places of detention outside of the criminal justice system and these could be located outside of existing hospitals. To date there has been a great reluctance to develop community-based alternatives on the grounds of public opposition. However there are instances in Northern Ireland and elsewhere of offenders being successfully rehabilitated into community services (Murphy and Fernando, 1999). In addition, more attention needs to be given to preventative social measures for at risk adolescents and young adults.

Conclusions

As Hospital provision is reconfigured to provide short-term assessment and treatment services, careful attention needs to be paid to the resettlement of patients with more complex needs and offending behaviours. This will require a much higher level of funding than has hitherto been available. Failure to do this will result in treatment beds becoming filled and the creation of a new-stay population as has happened in Scotland (Whorisky, 2002) .

Alternatively increasing numbers of these difficult patients could be placed in private hospitals (most likely in Great Britain) as is happening in England but at per annum costs in excess of £100,000 per person (Russell, personal communication, 2004).

Resettlements from long-stay hospitals

From the early 1980s, long-stay patients began to be resettled into hostels and other community facilities. Five studies have monitored the resettlements of these patients.

McGinnity, McVicker, Marriott et al (1990) followed the first 100 patients discharged from Muckamore Abbey Hospital in the period 1987 to 1992. All had been re-settled in the Northern Board area although nearly half came from other Board areas. In all, 88% went to nursing homes provided by the private sector and only 6% to voluntary accommodation; 5% statutory provision and one person lived independently. Over 90% of residents and 72% of relatives interviewed expressed satisfaction with the placement. However the authors noted that some people could move on to more independent living arrangements but "*there are clear gaps in provision and a definite possibility of people being "trapped" into a particular level and form of care*. (p.16).

Kavanagh (1994) reported on 73 clients who had moved from hospital to community settings. Data as obtained from semi-structured interviews with clients, staff members and relatives. A significant increase in adaptive functioning was noted along with a decrease in maladaptive behaviours. People with a learning disability had more contact with relatives in the new settings and expressed a preference for living there.

Donnelly et al (1997) reported on a random sample of 114 patients discharged from three hospitals in the period 1987 to 1990. Few of the sample had major problems with daily living skills and behavioural problems were also uncommon. Nevertheless around 70% were resettled into residential or nursing homes. Former patients were satisfied with their new homes and reported feeling happier, healthier and more independent since discharge. However social networks were poor and there was no evidence to suggest that people were undertaking new or ordinary daytime activities.

Donnelly et al (1996) followed up at 12 and 24 month intervals a group of 214 patients who had been discharged in the period 1990-1992 mostly into nursing homes (60%); residential homes (22%) and hostels/group homes (12%). Only five persons (2%) went into some form of independent living. Although little or no change was found in patient's competences, certain aspects of challenging behaviour had improved after 12 months. People were also less depressed and more satisfied with their new homes.

Few changes were found in their patterns of activities or social networks. The authors recommended that purchasers and providers in N. Ireland *"give more attention to ways in which the principles of normalisation could be incorporated in the process of contracting and delivering of services"* (p. 598).

McConkey et al (2002) followed up 68 patients from EHSSB area who were resettled from Muckamore Abbey Hospital period in the period 1996-2000. As in previous studies, nearly three-quarters of people moved from the Hospital to residential homes and a further 15% to nursing homes. Only eight persons moved to ordinary housing. Care-managers reported that only ten persons (15%) who were resettled had a choice of alternative accommodation open to them. At the follow-up date, four of the 68 were presently back in hospital with a further ten people having had one or more treatment admissions since discharge. The latter tended to be people with mental health and behaviour problems living in community settings.

Around half the people resettled were considered by staff as having challenging behaviours that they rated moderately serious or severe. These were mainly aggression to others and to self. However for 21 people (41%), staff thought that their behaviour problem had improved since the move although this was less evident in those with severely challenging behaviours.

Nearly all former patients who were interviewed were happy to have moved. Only one person said they had not wanted to move from the hospital and another wished they could move back there (McConkey et al, 2003).

Although a majority of families welcomed the move from the Hospital; a significant minority (26%) had been unhappy at the prospect of the move. After the move all families felt the residence was at least equivalent to the Hospital with over four out of five families rating it as much better than the Hospital (McConkey et al, 2003).

There was nearly a four-fold difference between the lowest cost package (£11,000 per annum and the most expensive (£41,500). The most expensive packages were in private residential homes. Nursing homes and statutory residential homes had lower cost packages. However when other sources of funding are added in, supported living arrangements in community settings are also among the highest in cost. These costs appear to be lower than those quoted for Great Britain (Emerson et al, 2000).

Costs incurred by Hospital-based multi-disciplinary teams in resettling patients was estimated in a study by Hughes et al, (2003) on one long-stay hospital. These ranged from £1,500 to £8,000 with an average of £3,400 per patient. The authors argue that these costs need to be factored in the overall monies allocated for resettlements.

Conclusions

- People were relocated mainly into congregated settings with little use made of more individualised options such as supported living arrangements. This continued in recent years despite the expressed policy of HSS Boards to community-based services (e.g. EHSSB, 1996).
- Although people were happier in their new accommodation, the dearth of social networks experienced by people in the new settings was marked.
- The failure of people to move on to more independent living arrangements despite them having the competence to do so and this need being identified by both key-workers and care-managers.
- The monies available for Northern Irish resettlements is less than in Great Britain.

Section 3: People living in residential accommodation and supported living.

In 2003, around 1,900 persons with a learning disability were living in some form of residential provision provided by both statutory and non-statutory agencies (McConkey, Spollen and Jamison, 2003).

Figure 2 shows the proportions of people living in three types of accommodation options.

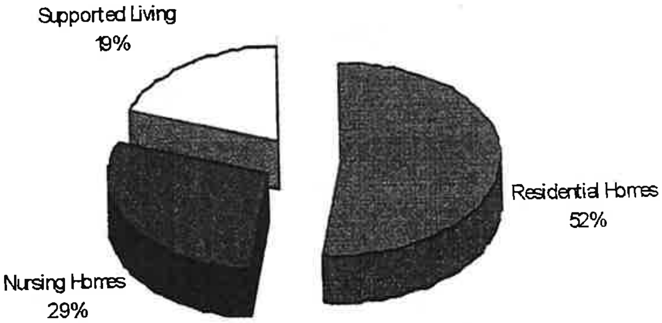

Figure 2: The proportions of people aged 20 years and over living in different accommodation options.

Around half of those in residential care were living in registered residential care homes. On average the homes have around 20 residents. Most people have their own bedroom.

Over one quarter live in registered nursing homes modelled on care of the elderly even though the average age of these residents is around 50 years. The proportion of nursing home places is higher in Northern Ireland than in England and Wales. In 1997, 7% of their places was in nursing homes (Emerson and Hatton, 2000).

A growing number of people live in supported living arrangements. The proportion is comparable to that for England and Wales (Emerson and Hatton, 2000). These individuals have tenancy agreements and live on their own or with one or two other persons. Support staff are on hand, with 24 hour cover provided as needed.

Around half of the residential the places (53%) were in the private sector; with 27% provided by voluntary agencies and 20% in statutory provision. However this distribution varies across Boards. The WHSSB has the highest proportion of private provision (93%) and the EHSSB lowest (28%). Voluntary provision is highest in the EHSSB (35%) and lowest in the WHSSB (7%). Statutory provision is also highest in the EHSSB although many of these are in supported living (36%).

However there is great variation across HSS Boards in the type of accommodation that they have available in their area[1]. For example, the NHSSB has the highest proportion of people in nursing home accommodation (46%) with the EHSSB (22%) and WHSSB the lowest (21%). The EHSSB has the highest proportion of people in supported living arrangements (31%) with the lowest proportions in WHSSB (4%) and SHSSB (3%).

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[1] This data is taken from a series of reports prepared for the NI Housing Executive and the four HSS Boards by McConkey and colleagues, 2000, 2001, 2003a, 2003b).

There is also proportionately more accommodation options in certain Trust areas than others; ranging from 6.8 places per 10,000 of population to 13.2 places per 10,000 (see Table 3). However none of the Trusts achieve the minimum number of places that the Department of Health has suggested for England and Wales, namely 15.5 places per 10,000. A wider range of geographical variation is reported in Great Britain: range 1 per 10,000 to 41 per 10,000: overall mean 15 per 10,000 (Office of the Deputy Prime Minister and Department of Health, 2002).

Table 3: The numbers of people in residential accommodation for each Community HSS Trust and the rate per 10,000 of the trust population (2001 census).

Trust	Trojan + Board updates	Rate per 10,000
Armagh & Dungannon	132	12.94
Craigavon & Banbridge	83*	6.80
Newry & Mourne	113*	12.99
SHSSB	**328***	**10.54**
Foyle	134	8.27
Sperrin Lakeland	149	12.52
WHSSB	**283**	**10.07**
Homefirst	346	10.55
Causeway	104	10.51
NHSSB	**450**	**10.54**
Down Lisburn	206	11.94
NW Belfast	190	13.24
SE Belfast	248	12.38
UCHT	179	11.97
EHSSB	**823**	**12.36**
Total NI	***1884****	***11.18****

* *these figures may be an underestimate as they may not include people living in statutory accommodation. There may be an extra 50 residents in Newry & Mourne and around 20 in Craigavon & Banbridge Trust.*

Of those living in these three forms of accommodation, the majority came to their present residence from living in a long-stay hospital (42%) and a further 25% from another residential facility. In all, 34% came from the family home. The average length of stay in residential accommodation was 7.0 to 8.3 years. This contrasts with the average stay of those still living in hospitals of 16 to 24 years (see earlier).

Recent research by McConkey and colleagues suggests that at least 12% of people in existing provision (220 persons) could be more suitably accommodated elsewhere; mostly in supported living arrangements. Moreover around 30% of the people in all existing options are likely to require extra support in the future as they age.

Characteristics of residents and tenants

In all, 51% were male and 49% female (which is different from the community population of 64% male and hospital population of 62% male). This may reflect a greater longevity of females coupled with more females being selected for resettlement than males (see earlier).

The mean age of residents was 48 years (significantly higher in WHSSB – 52 years; compared to SHSSB mean of 47 years). The age also varied significantly across

Trusts with UCHT having the lowest average age (41 years) and Foyle Trust highest (55 years). Table 4 shows the age bands of residents. Given a normal life expectancy which now seems likely for those aged over 20 years (see Chapter 1) this data suggests that over the next ten years only 25% of these residents are likely to die.

Table 4: The numbers and percent of residents by age groupings

Age Band	Numbers	Percent
0-19	9	0.7
20-24	42	3.0
25-29	56	4.0
30-44	425	30.2
45-59	502	35.6
60-64	138	9.8
65-74	146	10.4
75+	91	6.5
Total	**1409**	**100**
Missing	32	-
Total	**1441***	

**** Age information was not available for 400 persons***

Overall, around two-thirds of residents were considered by their key-workers to have mild/moderate learning disabilities and the other third to have severe/profound disabilities. However this breakdown varied by age bands as Table 5 shows.

Table 5: The proportion of residents by age and level of disability (Data based on census returns from four HSS Board Housing Studies (2000-2003) (N=1,528) (Data missing for 2% of cases).

Age Bands	Moderate*	Severe/Profound*
0-19	0.5%	0.5%
20-34	9%	7%
35-49	21%	10%
50+	36%	14%
Totals	**66.5%**	**31.5%**

**ratings used by key-workers*

The largest sub-grouping of residents are aged over 50 years with mild/moderate disabilities.

Evaluation of residential and supported living options

Despite the widespread use of residential and nursing home placements in Northern Ireland, there has been no evaluative studies that we could find into the impact these options had on the lives of residents. However studies undertaken in Great Britain and reviewed by Hatton and Emerson (1996) suggest that congregated living options do not provide residents with opportunities for developing their independence, nurturing friendships and promoting their social inclusion.

Maybin (2000) undertook an evaluation of the supported living services developed by Ulster Community and Hospitals Trust for 45 persons. This involved the relocation of residents in registered accommodation into their own tenancy with support staff provided by the Trust. Using information provided by tenants, relatives and professional workers, it was concluded that the tenants were happy, settled and achieving a higher level of functioning than in their previous accommodation. They were also leading 'normal' lives within their communities and staff were also reported to be happier and felt supported. One instance of an unsuccessful move was noted mainly due to the unsuitability of the selected neighbourhood.

Another study examined three supported living schemes in Northern Ireland (McConkey and McConaghie, 2001). These consisted of clusters of houses within one contained area with one or two tenants in each property which had opened from 1992 onwards in two rural towns and in a suburb of Belfast. Comparisons could be drawn with data reported for supported living schemes in England (Emerson et al, 2000) as the same measures were used.

In both N. Ireland and England, tenants were being supported with challenging behaviours, mental health problems and epilepsy although this was less evident in two of the three Northern Irish Schemes.

The tenants had more choices open to them and to enjoy life experiences comparable to those of non-disabled persons. Sizeable proportions had health checks carried out although not to the same extent as reported in Britain. There were concerns about the risks of abuse and exploitation that Northern Irish tenants might experience and in some instances these concerns appear to be higher than those reported in Britain.

However people in supported living per se did not experience any greater degree of social inclusion. For this to happen, these schemes need to integrate with a range of initiatives in employment, advocacy and befriending. In Northern Ireland, Triangle Housing Association has been active in developing such services.

The costs of the three schemes in N. Ireland fell into the lower range of costs reported for the British schemes and yet they appear to be serving a comparable tenant group and producing similar outcomes. In two of the schemes the costs were met entirely by housing monies and social security payments while in a third scheme, the HSS Trust contributed 20% of the costs. This contrasts sharply with the British schemes which were funded by a higher proportion of monies from health and local authorities.

Conclusions

- Significantly fewer residential places are provided for adult persons in Northern Ireland compared to Great Britain and the Republic of Ireland. Moreover the bulk of this accommodation is taken up by people relocated from Hospitals or other residential homes. Only one-third people have moved into the accommodation from family care.
- Residential care homes and nursing homes form the predominant model of provision in Northern Ireland even though the majority of persons are rated as mild/moderate disabilities. This model provides a relatively low-cost option but requires to be wholly funded by HPSS monies.
- The emerging supported living schemes show promise in terms of the improved quality of life they offer people with a learning disability and the value-for-money they provide for HPSS providers.

Section 4: People living with family carers

Close to 6,000 persons with a learning disability aged 19 years and over are living with family carers (McConkey and colleagues, 2000, 2002, 2003a, 2003b). Of these, nearly one third presently live with a single carer and over 25% with carers aged over 65 years. Around one in six carers were rated as being in poor health. These are all risk factors that make present care arrangements vulnerable and may necessitate alternative accommodation having to be found for the person, sometimes with little or no notice.

Over half of the families (54%) are dependent on State benefits as their main source of income and a further 6% were rated as having an income of less than £12,000 per annum. Of the remaining 40%, only 6% were rated to have an income in excess of £24,000.

Just over half of family carers live in owner-occupied accommodation (50% to 60% across the four HSS Boards) with the bulk of the remainder living in accommodation rented from the Housing Executive or Housing Associations. This proportion is much higher in certain HSS Trust areas than others, e.g. North & West Belfast 60% and Foyle 55% rented accommodation. However home ownership by families of people with a learning disability throughout Northern Ireland is lower than the regional average of 68%.

Trust staff rated present housing arrangements and inadequate or unsuitable for around 9% of families. The main shortcomings were lack space and overcrowding, and the need for better bathrooms and ground floor accommodation.

In Northern Ireland, the most common adaptations made to family homes have been the installation of showers, new bathrooms and toilets and safety devices. These have been paid for by the disabled person's family (33% of instances); the NI Housing Executive (31%) or by Health and Social Services (29%). Adaptations are twice as likely to be found in privately owned homes than those rented from the Executive or Housing Associations (Monteith, McLaughlin, Milner and Hamilton, 2002).

A particular concern has been the delays in obtaining means-tested grants for home adaptations and the degree of bureaucracy involved (Monteith et al, 2002).

Future needs

Community personnel from HSS trusts estimated that up to 1600 persons throughout Northern Ireland may require alternative accommodation and/or support arrangements in the coming five to ten years. Of these around 170 are likely to be required in the next two years. Half of these were in the EHSSB area.

An increase of 700 places in Northern Ireland would bring the overall ratio of provision to the *minimum* suggested for England (Office of the Deputy Prime Minister and Department of Health (2002) giving a total of 2,600 places: 1.55 per 1,000. This increase would make the proportion of people living in some form of residential accommodation similar to the proportion in the Irish Republic (see earlier).

An additional 2,000 places would bring it to the upper range suggested by the Department of Health of 2.33 places per 1,000.

The people whom trust staff saw as needing to move tended to live with older carers who were in poor health and whose housing was deemed inadequate. Hence the decision was not seen by Trust staff in terms of the availability of carers rather than on the demands placed on carers, such as a relative with challenging behaviours.

In all HSS Boards the number of people known to be on a waiting list for alternative accommodation was very low and never higher than 13% (EHSSB area) of those who were thought to require a move. This suggests that 'futures planning' is not occurring with these families (see later).

Trust staff felt that around half these persons could be relocated into some form of supported living arrangements – either on their own; with one or two friends or continuing to live in the family home – and up to 10% with another family member. Placement in a residential home was noted for around one quarter, although this option was more frequently mentioned in the WHSSB area perhaps because there are fewer supported living schemes in that area. Nursing home placements were recommended for around 8% and some form of specialist provision (usually because of challenging behaviours) for around another 8%.

Views of people with a learning disability

Research undertaken in Northern Ireland with 180 people attending 20 centres across Northern Ireland identified the features that were important to them in their living arrangements (McConkey et al, 2003). Just over half were living with family carers and the others in a range of other accommodations.

Four themes were common to all participants in regards of their living arrangements: they had their own room, they participated in household activities; they had access to community activities and contact with family and friends. People living with families mostly wanted to remain there.

Those living independently or in supported housing valued their independence and having access to support staff whereas those in residential homes spoke of the importance of their relationships with co-residents and staff.

Those living in ordinary housing – whether with families, independently or in supported tenancies - were more likely to report harassment and stressed the importance of living in a pleasant neighbourhood than did those in residential homes.

Consultations undertaken with people with a learning disability (Review of Learning Disability Services, 2004) identified a number of concerns. People often have no choice about where they live or whom they live with. They have no access to help and advice if they want to move. Staff members felt it was too risky for people to live on their own but people felt that they should have a chance to do so.

Carer's views

Four studies, using a range of methods, have been undertaken in Northern Ireland to ascertain carer's views (McConkey et al, 2003). In all, 387 carers responded.

The majority of carers envisaged the person continuing to be cared for within the family. The most commonly chosen out-of-home provision was in residential or nursing homes, supported living in their own homes and homes for small groups of people. Few carers chose living with another family.

However only small numbers of carers envisaged alternative provision being needed in the next two years and few had made any plans for alternative living arrangements.

The most frequently unmet need reported by carers was for their relative to have greater opportunities to take part in leisure activities; for day services and increased short break (respite) provision. These echo the views of parents with children (see Report of that Task Group).

Seltzer et al, (1996) examined the extent of future care planning done by carers aged 55 years and over. In a sample of 151 Northern Irish carers, 62% reported no plans having been made whereas comparable percentages for families in the Irish Republic was 39% and 13% for a sample in the United States. Moreover the US sample rated their health as being significantly better than the two Irish samples and they had lower levels of parenting stress. The Northern Irish mothers had the highest percentage of health problems that impeded everyday tasks and they had the highest levels of parenting stress.

In consultations held with carers as part of the Review (Bogues, 2004), they stressed their need for support to plan for the future of their relative when they were no longer able or available to do so. This offer of support needed to be restated over time as a refusal at one point might be overtaken by subsequent changes in family circumstances.

Carers did not want professionals to assume that other family members would take over the caring role and they were concerned that hospital resettlements would reduce the availability of funds to meet the resettlement needs of their relative.

A recurring theme was their need for greater support in their caring role through respite breaks, domiciliary help and the provision of a phone alarm link should anything happen to them.

Conclusions

- Families caring for a person with a learning disability tend to be poor; around half live on State benefits and more reside in rented accommodation than is the case within Northern Ireland as a whole. Nearly one third of carers are lone parents.
- Living with their own families is the preference of people with a learning disability and the hope of many parents. However there was evidence that support services to families with adults as well as with children need to be improved.
- People with a learning disability want to maintain contact with family and friends if they have to move from the family home. They prefer to live in homely accommodation and to be involved in household tasks and community activities.
- Carers are willing to consider a range of accommodation options as being suitable for their relative and increasing numbers appear to be interested in making future plans which could include options outside the family circle.

Section 5: International Research

In recent years, a growing literature has emerged on the experiences of people living in different accommodation and support options and the impact these have on their lives. There are clear differences among the different models that are commonly used. This data should help to inform future commissioning decisions.

Congregated models of care

Current residential services in UK and Ireland for people with a learning disability tend to be dominated by settings that are larger than 'ordinary homes'. Emerson and Hatton (2000) undertook an analysis of the 1997 Census of residential accommodation in England and Wales. This suggested that only 13% of adults lived in homes with less than 5 persons; 38% were in homes with between 5-9 persons and nearly half (49%) lived in settings with 10 people or more. Likewise following hospital resettlement programmes, very few people (4%) were found to be living independently (Cambridge et al, 1994).

In recent resettlements from a hospital in Scotland, an increased use of smaller accommodation units is evident, in that 8% of people moved into a single person flat and a total of 55% of people moved into accommodation for five or less people. However 25% of people moved into accommodation for between 6-10 people and the remaining 25% of people moved into facilities with 36 or more people living there. Interestingly, the people moving into the larger facilities, although older, were not assessed has having the greatest degree of behaviour problems nor the highest level of dependency (Ager et al., 2001).

The move from hospital to community settings has been largely positive for people with a learning disability, especially in their adaptive behaviour scores and opportunities to take part in a wider range of leisure pursuits (Emerson and Hatton, 1994; Donnelly et al, 1996). However, sustained improvements in challenging behaviours and increased social integration are not commonly reported (Ager et al., 2001). As most people were resettled into nursing homes and residential accommodation with 10 plus residents, these findings are not unexpected.

Although there has been a paucity of UK studies specifically focussing on nursing home provision; one study in N. America followed nearly 250 persons over a three year period - 50 of whom had moved into smaller community settings and the remainder stayed in nursing homes. It was found that those in community settings had better health and greater levels of community integration (Heller et al, 1998).

With resettlement programmes nearing completion in Great Britain, recent research literature on the topic of housing has focussed on three main themes:

- Special residential (village) communities
- An evaluation of small group homes
- Supported Living models.

1. Special residential (village) communities

As part of the Hospital closure and redevelopment programmes, special campus-style accommodation was developed by the NHS as an option particularly for clients who had additional and complex needs. Typically these consisted of a cluster of houses for six to eight persons on the same site. This option had a number of attractions; it provided economies of scale to commissioners while carers saw it as offering a more protective environment for their relatives. However proponents of an ordinary life philosophy warned of the danger of recreating mini-institutions. The Department of Health commissioned a major research project to identify the possible advantages of this model of provision alongside two others; 'village' (or intentional) communities such as Camphill where people lived in communities alongside able-bodied co-workers often in rural settings and community-based residential supports in dispersed housing schemes (Emerson et al; 2000).

The best examples of each type of model was sought through consultations with expert informants throughout England and the data analyses conducted by the researchers took account of differences in the characteristics of clients in the different settings.

All options were considered to have some advantages as well as disadvantages. However the residential campuses providing fewest benefits despite being selected as representing the best examples of this model of service provision. The distinct features of the residential campus model were:

- More likely to be supported by senior staff with nursing qualifications;
- Better organisational procedures for assessment and treatment.
- More residents had a general health check in the last year and a vision check in the last two years.
- Staff consider residents to be less at risk of exploitation fro members of the public.

However many more benefits were found for people in the other two models of provision.

For example, village communities that had a strong value base provided more health checks, more routine day activities, less institutionalised routines, had higher quality person-centred planning and also training and supervision of staff.

2. Small Group Homes

A common model internationally has been a small group of people with a learning disability sharing an ordinary house with staff support available on a 24 hour basis if required.

The research project described above (Emerson et al 2000) found that in the main, people living in dispersed housing in community settings were more likely to:

- live in homely environments;
- had increased access to independent advocacy;
- involved higher quality person-centred planning procedures;
- had more overall choice in the way they were supported;
- had larger social networks
- and have care which was rated as less institutionalised.

An important review of the small group home model conducted by Hatton and Emerson in 1997 concluded that, "it is clear that smaller community-based homes are associated with better performance and more positive outcomes than either hostels or hospitals".

Nonetheless small group homes are not consistently good and the quality of the settings is variable. The best determinant of quality appears to be the way staff support individual service-users. Improvement of services requires a management emphasis on staff training, leadership and practice instead of focussing on buildings and location (Mansell, 1998).

Felce and colleagues (1998) also argue that a combination of person-centred planning with activity planning and staff training, will yield results better than 'further appeals to ordinariness." Staff training in providing 'active support' appears a particularly effective approach to promoting opportunities for people with severe disabilities (Jones et al., 1999). These views are echoed by Simons (1998a) who identified variability in the quality of small group homes / staffed housing, the relative isolation of people living there and an insufficient number of services as recurrent difficulties with this model. He also highlighted that a focus on form and not content, poor management and the lack of, or poor quality with individual planning as main reasons for the failure of these models to improve the quality of life for people with a learning disability. These are factors which should be taken into account in a Best Value assessment (Cambridge, 2000).

3. Supported Living

"Supported living is primarily about enabling people with a learning disability to be actively engaged citizens through:

- Supporting them to live in their own homes (owned or rented by them)
- Enabling them to participate in their communities (for example through working if they wish)" (Simons and Watson, 1999: p.41).

However Simons and Watson acknowledged that this is not a single model and that this can lead to some difficulties in understanding the principles involved.

Proponents of this model argue that it is built around five principles; separating out housing and support, focusing on one person at a time, providing as much choice and control for service users as possible, zero rejection (not giving up on people), a focus on relationships and acting in ways which complement natural supports rather than simply replacing them (Kinsella, 1993). Hence supported living is more than de-registering homes and giving people their own tenancy which has tended to be the two main consequences of the implementation of the new Supporting People funding arrangements.

The research carried out by Emerson et al (2000) identified the following as advantages of supported living over group homes and residential campuses:

- people are more likely to have tenancy agreements;
- they tend to deliver more intensive staffing;
- there are better internal procedures for allocating staff support on the basis of the needs of tenants;
- evidence of greater tenant's choice (especially over where and with whom they live).
- better social integration and access to leisure and recreational activities

The disadvantages compared to other models were found to be:

- fewer hours of scheduled activity;
- more likelihood of having their home vandalised;

- poorer implementation of habilitative procedures such as individual plans; key-workers and reviews.

Despite, these disadvantages it is widely acknowledged that supported housing adds important options to the range of possibilities for providing support and accommodation for people with a learning disability (Simons and Watson, 1999; Mansell, 1998).

New models of provision

A number of emergent models are being explored in order to widen the range of service options for people with a learning disability. Some of these are better established in North America and continental Europe than they are in these islands. However a recent publication by the Foundation for People with Learning Disabilities (2001) described these options using British case studies.

Adult Placement Schemes

There is a long history of people with a learning disability living with substitute families; for example boarding arrangements of patients from hospitals were common in Scotland from the 1930s onwards. More recently this notion has been formalised in schemes in which families or carers are actively recruited, supported and paid to provide a long-term homes for selected individuals. Although certain problems have been identified, on the whole such schemes did fulfil the aspiration of people to be part of a family and they were preferred over other care arrangements (Robinson and Simon, 1996). In Northern Ireland to date, this model has been used successfully but more for short-term breaks rather than longer-term placements (Roberts, 1998, McConkey et al, 2004).

Networks of Support

These schemes are suited to people with low level needs but who may need intermittent support. Around nine people form the network and all have each other's phone numbers. In addition community living workers are recruited from the same area and are paid to give around 10 hours support per week to the network members. In addition telephone support is provided at evenings and weekends (Simons, 1998b).

Home Ownership

The capital costs of acquiring a property can be obtained through a mortgage funded by Income Support payments (Simons 2000). Mencap's Golden Lane Housing is one of the organisations pioneering this scheme. There are also possible co-ownership options with Housing Associations. Some individuals may inherit a property from their family but this needs to be carefully planned in advance (Simons and Watson, 1999). However one drawback can be funding the maintenance costs of the building.

Personal Assistants

Direct payment schemes may make it possible for people with disabilities to recruit and employ their own personal assistants. Although this is becoming more common for people with physical disabilities, there are few instances of this occurring for people with a learning disability (Holman and Collins, 1998). However those who have experience of them are broadly favourable (Gramlich et al., 2002).

Sheltered Housing for the Elderly

In N. Ireland, there have been instances of an aging carer and their son/daughter with a learning disability both moving into sheltered accommodation for the elderly. If the carer dies, the relative may continue to live there with augmented staff support as required. Similarly aging carers might move with their relative into services provided primarily for people with a learning disability.

Housing models – Conclusions based on research findings

Emerson et al (2000) concluded that "residential campuses" offered a significantly poorer quality of care and quality of life than community-based, dispersed housing schemes". Moreover, they felt that "village communities operated by independent sector organisations should continue to be included on any 'permissive list' of acceptable options for the provision of residential supports". They went on to note that:

"comparison of the costs and benefits associated with supported living and more traditional small scale, community based provision, indicate that it would be appropriate to include supported living schemes in any future list of permissible options".

Simons and Watson (1999) also supported the further development of supported living options and concluded that it 'claimed to be a practical as well as principled option' (p47). However they highlight the need to clearly define the concept of supported living and caution against viewing it as a panacea, highlighting that in particular it does not necessarily appear to lead to people being active participants in their communities and the actual operations of any scheme need to be clearly defined.

Howard (1996) found that supported living arrangements most effectively supported people with complex needs when services included – a sustained commitment to individuals combined with skilled personal care, clear identification of risk behaviours and strategies to appropriately manage such risk and the ability to mobilise additional problem solving resources and skilled assistance at short notice.

On the basis of a review of current literature Simons and Watson (1999) concluded that a 'modernised' housing and support service would have the characteristics listed in the Box below.

A modernised housing and support service would ...

☐ Be based on the principles of citizenship and civil rights
☐ Be comprehensive and inclusive
☐ Draw on a synthesis of the supported living models and developments like 'active' support
☐ Be based on person centred planning, along with community development strategies to open up a wider range of opportunities
☐ Take the issue of self determination seriously
☐ Use resources efficiently and flexibly
☐ Require the creation of a coherent funding base
☐ Involve regulatory reform
☐ Be complemented by a range of other services (including employment, continuing education and supported leisure services)

Commissioning Guidance issued to English authorities

In 2002 the Department of Health issued draft guidance to English local authorities based on the past research findings (Office of the Deputy Prime Minister and

Department of Health, 2002). They identified three key messages relevant to developing a housing and support strategy:

- Smaller community-based housing and support services provide higher quality support and better outcomes for people with a learning disability than larger more 'institutional' forms of provision.
- The quality of support and outcomes provided by existing community-based housing and support services is often unacceptable when judged against the aspirations of choice, social inclusion and promoting independence.
- There are few robust relationships between measures of resource input and either the quality of support or outcomes for people with a learning disability. Quality is determined by how resources are used. Further research is needed into the cost-benefits of service models and particularly into the roles of staff and managers in producing valued outcomes for tenants and residents.

Special Needs Housing

The main emphasis in the literature has been on different forms of residential accommodation and support they offer to individuals. Very little analysis has been made of the physical requirements in housing but a summary of the main conclusions now follows.

Most attention appears to have been paid to the adaptations required in ordinary housing to assist families caring for a child or adult person with physical and/or sensorial disabilities (e.g. Beresford and Oldman, 2002).

Here the main issues highlighted were:

- Families with disabled children experience far greater problems with their housing than families with non-disabled children. Nine out of ten families reported at least one difficulty with their housing and many reported multiple problems. Families on low incomes experienced most problems.
- Many families would prefer to deal with their housing problems by moving rather than adapting their current home. Over one third of families found the location of their home to be a problem either because it was an unsafe place of the child or because of difficulties with neighbours.
- They needed extra space in the house to allow for use of wheelchairs and walking aids; storage space for aids and equipment; privacy or time-out space, play space and for carrying out therapies.
- Downstairs toilet, well-designed bathrooms to allow easy use of lifting or mobility aids.
- Ground floor bedrooms, kitchens designed with safety as well as access in mind.
- Easily-managed stairs – installation of chair lift
- Suitable gardens, car parking, located on level ground – not on steep hills and located close to services.

The report noted that only 10% families had received assistance from statutory agencies in order to address their housing needs. Typically there was no single agency or department with lead responsibility for meeting the housing needs of disabled persons living with families.

Challenging behaviours

With regard to housing for persons prone to exhibit challenging behaviours such as screaming; destruction of property and aggression to others; the following recommendations have been noted (Felce et al, 1998):

- Separate living area available as well as bedroom;
- Sound-proofing
- Flexi-glass installed and strengthened fabric such as doors
- Secure outdoor space available
- Use of detached properties with large gardens; distanced from neighbours
- Small number of residents sharing

For people with dementia and other who may be inclined to wander, sensors can be fitted to external doors to alert staff.

Housing clusters

Little evaluation appears to have been undertaken of the impact of the physical grouping of special needs housing. The so-called 'core and cluster' model is well known; in which a staff team works from a central base – such as a residence that is staffed 24 hours - to support people living in close proximity in their own homes. However there appears to have no evaluations of this model undertaken for people with a learning disability.

Two cautions have been noted. The cluster houses need to be well dispersed in the neighbourhood in order to avoid a segregated 'campus' facility developing by default. (Heller et al 1998b). Second, it is questionable whether the same staff team can successfully combine the different roles needed in the two settings.

Another issue that has been alluded to is the danger of different special needs groups being housed in the same locality. However no formal evaluations appear to have been undertaken on this issue.

Some housing providers have begun to experiment with new styles of buildings so that within the same complex, there can a range of accommodation suited to people's needs, such as self-contained flats for one or two people as well as traditional shared housing arrangements with staff always available. Again, these developments are novel and little formal evaluation appears to have been undertaken as to whether or not they live up their intentions. It is likely that very determined efforts would be needed to ensure that they do not become another form of congregated living arrangements – albeit with better standards of housing - with all the disadvantages that are known to flow from this model.

Finally, it is apparent that advances in computer-assisted technology, communications and alarm systems will enable many people with physical and sensorial disabilities to be less dependent on people living with them and assisting with their daily living needs. A telephone support line can provide constant emergency contact over 24 hours with personnel available to visit if required.

Modem technology promises further extensions, such as the use of video-phones and control of electrical equipment. These means could be used to maintain people in the family home when the carer dies or reduce to need for face-to-face support. However these can represent a significant capital investment at present and they are prone to breakdowns.

The costs of housing and support

In recent times a variety of sources have been used to fund housing and support services. In Great Britain, these can include funds paid separately from Health Authorities and Social Service/Social Work (whereas only one source of funding is available in N. Ireland) as well as income maintenance benefits; disability benefits; housing benefits and housing subsidies (Simons and Watson, 1999). But these changed in 2003 with the introduction of Supporting People arrangements.

Research into the costs and factors that determine costs have been remarkably rare in view of the scale of expenditure on residential services. Of work done to date, a number of conclusions can be drawn (Felce, 1996).

- Cost variation is considerable, even between services of similar types.
- Generally costs increase with more dependent clients. However there is only a weak link between resident needs and the determination of staffing. It appears that providers when determining staffing levels use inconsistent criteria
- Independent sector costs tend to be lower than statutory sector.
- Community housing costs are generally greater than those of hospitals but they produce better outcomes.
- Economies of scale do not appear to operate in facilities larger than six and there may be no cost disadvantages in providing smaller settings down to three persons.

The largest element of the revenue costs of services is attributable to staffing. The majority of economic evaluations of specific forms of support services for people with a learning disability (e.g., residential supports) have reported a modest positive association between indicators of 'need' and the costs of staff-user ratios of provision. People with greater needs usually have more greater levels of staffing.

However there is no simple correlation between the amount of money spent on services and the outcomes attained. This involves taking into account differences between services in the needs of people served, especially as there is extensive evidence to suggest that people with greater or more complex needs often experience poorer outcomes. The findings of the few studies that have attempted to examine costs-benefits suggest that the link between resources (costs or staff-user ratios) on the one hand and quality on the other is tenuous. Some studies have reported that increased resources are linked to an extent with increased quality but others have failed to find a link at all (National Assembly of Wales, 2002).

Supporting People

In April 2003, new arrangements came into place in Northern Ireland for setting up, monitoring and funding housing support services. The 'Supporting People' initiative is managed by the Northern Ireland Housing Executive in partnership with a range of agencies such as HSS Boards, local government, support services and users.

The aim is to make the process of setting up housing related support services less complex and no longer is funding for support attached to the tenure or accommodation the person occupies. Support can be provided in a range of accommodation options including supported housing, hostel-type accommodation and independent living, as well a new type of 'floating support' where support funding is linked to the individual rather than to the accommodation. Support systems can also be varied in intensity as client needs change.

Supporting People has two separate funding 'pots'. Housing Benefit which only pays for the housing costs (from the benefits section of NIHE) and new block grants for the cost of support services to vulnerable people. These will be financed from various existing streams brought together in one pot, such as transitional housing benefits and income support, and special needs management allowances. Supporting People monies are cash-limited.

All providers must have accredited status in order to provide support services and they will be subject to monitoring and scheme reviews to determine that they meet the Supporting People Standards, notably quality and cost-effectiveness in the delivery of services.

Experience in Great Britain

Prior to the implementation of Supporting People in Great Britain, a study by Watson et al, (2003) expressed concerns that service commissioners lacked agreed definitions of marginal, hard-to-reach or high-risk groups such as individuals with complex and multiple needs. Also lacking was a systematic needs analysis showing demand pressures, exclusions and service-user's preferences along with an understanding of service options.

In February 2004, the Government published the results of an independent review of Supporting People (www.odpm.gov.uk). This found that although Supporting People was funding many valuable services, the unit costs varied widely among local authorities. It recommended that efficiency savings should be made starting in 2004/5. Further research and analysis of spending by high cost local authorities is proposed and the development of a new allocation formula.

Other funding sources

The Department of Health (2002) note the following funding sources that can also be accessed alongside or instead of Supporting People monies.

Direct Payments: HSS Trusts can offer people cash payments as an alternative to arranging for social care services, so that they themselves can purchase the relevant services. These payments can be made available to adults over 16 years of age; parents of carers of disabled children and to carers aged 16 and over in respect of carers' services.

Independent Living Fund: This is an independent trust funded by the Department for Work and Pensions which helps to subsidise the cost of intensive home packages. To be eligible the disabled person must be in receipt of higher rate DLA and have been assessed as needing £200 or more of social service support. The HSS Trust must make a minimum contribution of £200 a week but this can take the form of directly commissioned services or Direct Payments.

Home ownership: Although a possibility for people with a learning disability it is not a straightforward process. Detailed advice needs to be taken and finding a lawyer competent in this area can be difficult. However home ownership can either full or shared; e.g. with a family member, co-habittee or Housing Association. Mortgages can be obtained through banks on the basis on personal income including benefits. Trust funds set up by families are another way of repaying mortgages.

Planning for the Future

To date, much of the planning into the housing and support needs of people with a learning disability in the UK has focussed solely on the resettlement of people from long-stay hospitals. The needs of persons living with family carers or in their own accommodation have been addressed largely through reaction to crises.

Both of these strategies distort the type and quantum of provision that is provided within a given locality. The old 'long-stay' population have needs and aspirations that differ markedly from people who have never been institutionalised. Accommodation options that suit them may become redundant in meeting the future needs of people living in community settings. Likewise people who require an urgent placement in a crisis end up in whatever accommodation is available rather than the sort that is best suited to their needs and wishes.

In England, the Department of Health (2002) recognised that "*current provision falls far short of demand and need ... and that the quality of life experienced by many people living in community-based housing and support services continues to fall short of the aspirations underlying current policy*" (p.1).

In 2002, they issued draft implementation guidance to local authorities (Office of the Deputy Prime Minister and Department of Health, 2002) which placed a requirement on Partnership Boards[2] to develop a local *Housing Strategy* for people with disabilities that will identify plans for the future commissioning of care and support services. This was to be done through effective links with local Supporting People teams and Local Housing Authorities.

The following tasks were to be undertaken:

- *Assess the contribution made by, and the effectiveness of current services.* This would entail mapping local housing supply for people with a learning disability; notably inequalities in current system of provision and the range of options available;
- *Finding out what people want and need.* This would involve undertaking a needs analysis based on information from consultations with local people who have a learning disability, their families and other stake-holders along with local information on current and projected needs, e.g. from survey data.
- *Work out the service changes or developments that might be needed.* Plans should be developed in the context of evidence on good practice, cost-effectiveness, statutory requirements, policy guidance and national and local performance indicators.

Recommendations are given for how these tasks might be undertaken, including pro formas for gathering information about client needs. The plans were to be submitted by winter 2002/2003. However current guidance does not make clear the next steps in the process.

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[2] *Partnership Boards are the main vehicle proposed by the Department for the implementing the changes recommended in Valuing People. They operate under the general guidance of Local Strategic Partnerships and bring together relevant statutory services, people with learning disabilities and family carers.*

The Department predicts that on the basis of past policy, research and expert opinion the level of provision of housing and support services required is equivalent to between 1.55 and 2.35 places per 1,000 of the adult population (aged 16+). These estimates are based on research reported by Braddock et al., (2001) as well as expert opinion documented by the Mental Health Foundation (1996).

Conclusions

The last two decades have seen a major sea-change in thinking about service provision for people with a learning disability; albeit within the context of increasing demand and inevitable resource-constraints within Health and Social Services.

It is highly unlikely that a return to institutionalised provision could be advocated for this group, even if there were financial gains to be had, which in itself is a most unlikely proposition.

There is widespread agreement that current housing and support services in the UK are inadequate in terms of quantity and the quality of life they offer. The trend towards supported living arrangements in which people with a learning disability hold tenancies or are owner-occupiers is likely to gain momentum underpinned as it is by equality legislation and practices. There is greater likelihood that these options will provide for a better quality of life for people with a learning disability although more efforts will be needed to maximise the opportunities they present for greater social inclusion.

There is greater recognition of the need for improved future planning and new funding arrangements should make it easier to provide a wider range of housing and support options. However significantly increased resources will be required to ensure that hospital resettlements are completed; that the standards of existing residential provision are improved and most significantly of all, the increased number of places that will be required in Northern Ireland as ageing carers pass on.

References

Ager, A., Myers, F., Kerr, P., Myles, S., Green, A. (2001) Moving Home: social integration for adults with intellectual disabilities resettling into community provision. *Journal of Applied Research in Intellectual Disabilities*, 14, 392-400.

Beresford, B. and Oldman, C. (2002) *Housing matters: National evidence relating to disabled children and their housing*. York – Joseph Rowntree Foundation: Policy Press.

Bogues, S. (2004) *Focus on Families: Message from Family Carers*. Belfast: Review of Mental Health and Learning Disability (NI).

Bradock, D., Emerson, E., Felce, D. and Stancliffe, R. (2001) The living circumstances of children and adults with mental retardation or developmental disabilities in the United Staes, Canada, England and Wales, and Australia. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 115-121.

Cambridge, P. (2000) Using 'best value' in purchasing and providing services for people with learning disabilities. *British Journal of Learning Disabilities*, 28, 31-37.

Cambridge, P., Hayes, L. and Knapp, M. (1994) *Care in the community: five years on*. Aldershot: Ashgate Publishing.

Day, K. (1993): Mental health services for people with mental retardation: a framework for the future. Journal of Intellectual Disability Research, 37 (Supplement, 1), 7-15.

Department of Health (2001) Valuing People: A New Strategy for Learning Disability for the 21st Century: Implementation. HAC 2001/016 LAC (2001)23. London: Department of Health.

Donnelly, M., McGilloway, S., Mays, N. et al (1996) One and two years outcomes for adults with learning disabilities discharged to the community. *British Journal of Psychiatry*, 168, 598-606.

Donnelly, M., McGilloway, S., Mays, N. et al (1997) A three to six-year follow-up of former long-stay residents of mental handicap hospitals in Northern Ireland. *British Journal of Clinical Psychology*, 36, 585-600.

EHSSB (1996) A Model of Community Based Services for People with Learning Disabilities. Belfast: Eastern Health and Social Services Board.

Emerson, E. and Hatton, C. (2000) Residential supports for people with learning disabilities in 1997 in England. *Tizard Learning Disability Review*, 5, 41-44.

Emerson, E., Robertson, J., Gregory, N., Hatton, C., et al. (2000) The quality and costs of village communities, residential campuses and community-based residential supports for people with learning disabilities. *Tizard Learning Disability Review*. 5, 5-16.

Felce, D. (1996) Community housing costs. Tizard learning Disability Review, 1,1, 4-11.

Felce, D. (1998) The determinants of staff and resident activity in residential services for people with severe intellectual disability: moving beyond size, building design, location and number of staff. Journal of Intellectual and Developmental Disability, 23 (2), 103-119.

Felce, D., Grant, G., Todd, S., Ramcharan, P., et al. (1998) *Towards a full life: research on policy innovation for people with learning disabilities*. Oxford: Butterworth-Heinemann.

Felce, D., Lowe, K., Perry, J., Baxter, E., et al (1998) Service support to people in Wales with severe intellectual disability and the most severe challenging behaviours: processes, outcomes and costs. *Journal of Intellectual Disability Research*, 42, 390-408

Foundation for People with Learning Disabilities (2001) *Get Moving: Making a choice about where to live*. London: The Mental Health Foundation.

Fraser, W.I. (2002) Forensic learning difficulties – the evidence base: Executive Summary. Journal of Intellectual Disability Research, 46, Supplement 1, 1-5.

Gramlich S, McBride G, Snelham N and Myers B with Williams V and Simons K (2002) *Journey to Independence –What self advocates tell us about direct payments programmes – a Joint Research Project from Swindon People First and the Norah Fry Research Centre.* Kidderminster; British Institute of Learning Disabilities

Hatton, C. and Emerson, E. (1996) *Residential provision for people with learning disabilities: a research review.* Manchester: Hester Adrian Research Centre.

Health Research Board (2003) *National Intellectual Disability Database: Annual report 2001.* Dublin, Health Research Board.

Heller, T., Factor, A., Hsieh,K, and Kahn, J. (1998) Impact of age and transitions out of nursing home for adults with developmental disabilities. *American Journal on Mental Retardation*, 103

Heller, T., Miller, A.B. and Factor, A. (1998b) Environmental characteristics of nursing homes and community-based settings, and the well-being of adults with intellectual; disability. *Journal of Intellectual Disability Research*, 42, 418-428.

Holman, A. and Collins, J. (1998) Choice and control: Making direct payments work for people with learning difficulties. In L. Ward (ed.) *Innovations in advocacy and support for people with intellectual disabilities.* Chorley: Lisieux Hall Publications.

Howard, J. (1996) A home of your own: moving from community residential services to supported living for people with learning disabilities in the North West. *Tizard Learning Disability Review*, 1, 18-25

Hughes, D., McGinnity, M., Kell, J., Kennedy, O. & Donnelly, M. (2003) Costing the hospital-based process of resettling people with learning disability in the community. *Irish Journal of Psychological Medicine,* 20 (2), 41-44

International Association for the Scientific Study of Intellectual Disabilities (IASSID) 2000): Mental health and intellectual disabilities: Addressing the mental health needs of people with intellectual disabilities. Report by the Mental Health Special Interest Research Group of IASSID to the World Health Organisation.

Jones, E., Perry, J., Lowe, K., Felce, D., et al. (1999) Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: the impact of training staff in active support. *Journal of Intellectual Disability Research.* 43, 164-178.

Kavanagh, M. (1994) Quality of life for people with mental handicap following deinstitutionalisation – An exploration from the 'Eye of the Beholder'. Unpublished Masters Thesis, Queen's University Belfast.

Kavanagh, S.M. and Opit, L.J (1999) The prevalence and balance of care for intellectual disability: secondary analyses of the OPCS disability services. *Journal of Applied Research in Intellectual Disabilities,* 12 (2), 127-148

Kinsella, P. (1993) *Supported living: a new paradigm.* Manchester: National Development Team.

McConkey, R. and Barr, O. (2000) *Future Housing and Support Needs of People with Learning Disabilities and their Families:* A Report to the Northern Health and Social Services Board and the Northern Ireland Housing Executive. Belfast: NIHE.

McConkey, R. and Barr, O. (2002) *Opening Doors: Recommendations for future housing and support options for people with learning disabilities in the W.H.S.S.B. area.* Belfast: NIHE.

McConkey, R. and Marriott, C. (2001) *Specialist Assessment and Treatment Project for People with Learning Disabilities and Additional Needs.* Final Report

McConkey, R., Milligan, V. and Madden, E. (2003a) *Future housing and support options for people with learning disabilities in the S.H.S.S.B. area.* Belfast: NIHE.

McConkey, R., Madden, E. and Milligan, V. (2003b) *Future housing and support options for people with learning disabilities in the E.H.S.S.B. area.* Belfast: NIHE.

McConkey, R. and McConaghie, J. (2001) *Supported Living: An evaluation of three schemes in Northern Ireland for people with learning disabilities.* Ballymoney: Triangle Housing Association.

McConkey, R., McConaghie, J., Mezza, F. and Wilson, J. (2000) *Moving on from Muckamore Abbey Hospital: The outcomes and lessons as perceived by people with learning disabilities; their key-workers, care managers and relatives.* Belfast: EHSSB.

McConkey, R., McConaghie, J., Mezza, F. and Wilson, J. (2003) Moving from long-stay hospitals: the views of Northern Irish patients and relatives. *Journal of Learning Disabilities, 7, 78-93.*

McConkey, R., Spollen, M. and Jamison, J. (2003). *Administrative prevalence of learning disability in Northern Ireland.* Belfast, DHSSPS.

McGinnity, M.,McVicker, R., Marriott, C., May, M. and O'Boyle, J. (1990) *Follow-up of patients resettled into the Northern Board area 1987-1992* . Unpublished paper: Muckamore Abbey Hospital.

Mansell, J. (1998) Getting a foot in the door: the strategic significance of supported living. *Tizard Learning Disability Review*, 3.

Maybin, M (2000) *Supported living scheme evaluation.* Newtownards: Ulster Community and Hospital Trust.

Mental Health Foundation (1996) *Building Expectations: Opportunities and services for people with a learning disability.* London: Mental Health Foundation

Monteith, M., McLaughlin, E., Milner, S. and Hamilton, L. (2002) *Is anyone listening?* Belfast: Barnardo's.

Murphy, G and Fernando, S. (1999) Services for people, with challenging behaviour and mental health needs at risk of offending. Tizard Learning Disability Review, 4, 3, 31-39.

Office of the Deputy Prime Minister and Department of Health (2002) *Housing and Support Options for People with Learning Disabilities. Draft guidance*. Available at: http://www.valuingpeople.gov.uk/housing.htm

National Assembly for Wales Learning Disability Advisory Group (2001) *Fulfilling the Promises.* Cardiff: National Assembly for Wales.

Review of Learning Disability (2004) *We have a Dream…Messages from People with a Learning Disability to the Review.* Belfast, Review of Mental Health and Learning Disability (NI).

Roberts, P. (1998) Developing an adult placement service for people with a learning disability. In challenge and change: Celebrating good practice in social work in N.Ireland. Belfast, CCEETSW,.

Robinson C & Simons K (1996) *In Safe Hands ? Quality and Regulation in Adult Placements for People with Learning Difficulties*. Sheffield: Joint Unit for Social Services Research.

Seltzer, M.M., Krauss, M.W., Walsh, P., Conliffe, C., Larson, B., Birkbeck, G. (1995) Cross national comparisons of ageing mothers of adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 39 (5), 408-418

Simons, K. (1998a) Getting a foot in the door: the strategic significance of Supported Living. *Tizard Learning Disability Review*, 3(2)7-16.

Simons, K. (1998b) *Living support networks: An evaluation of the services provided by KeyRing*. Brighton: Pavilion Publishing.

Simons K (2000) *Pushing open the door; Housing Options: the impact of a 'housing and support' advisory service.* Bristol : The Policy Press for the Joseph Rowntree Foundation.

Simons, K. and Watson, D. (1999) *The view from Arthur's Seat: Review of services for people with learning disabilities – a literature review of housing and support options beyond Scotland.* Edinburgh: Scottish Executive Central research Unit.

Simpson, M.K. and Hogg, J. (2001) Patterns of offending among people with intellectual disability: A systematic review. Part 1: Methodology and prevalence data. Journal of Intellectual Disability Research, 45, 384-398

Slevin, E., McConkey, R., Irwin, D., Reaney, E. (2002) *An evaluation of a hospital for people with learning disabilities - future assessment and treatment needs.* Report for SHSSB

Watson, L., Tarpey, M., Alexander, K. and Humphreys, C. (2003) *Supporting People: real change? Planning housing and support for marginal groups.* York: Joseph Rowntree Foundation.

Whoriskey, M. (2003) Progress with learning disability hospital closures in Scotland. *Tizard Learning Disability Review,* 8 (1), 4-9

Chapter 4:
Day Opportunities for People with a Learning Disability

Overview

In the United Kingdom over the past 20 years and more, Government policy in learning disability has been dominated by the resettlement of patients from long-stay hospitals. This in turn has led to increased scrutiny of the various models of residential services that is offered to this client group.

By contrast, there has been little radical change in the provision of day services, although as Simons and Watson (1999a) noted: "*the way day services are currently organised is widely perceived to be problematic; there is a collective disaffection with current arrangements*" (p.7). These authors also note that "*there is relatively little evidence about the outcomes achieved by different models of provision ... many forms of day service are largely unevaluated*" (p.5).

Although research is limited, the evidence does suggest that centres under-perform in terms of the outcomes they offer to people with a learning disability; they perpetuate a segregated model of provision that is increasingly out of tune with modern values and they do little to enable people to form relationships within their communities. These truisms should encourage a critical review of existing expenditure in day centres and caution against extending this model of provision.

There is a growing consensus of the need to widen the range of options available beyond day centre attendance. This includes Further Education, Vocational Training, Work experience, Paid Employment, Voluntary work, Social and Leisure activities. However these alternatives are not without their difficulties. The range of choices is not always available in any one locality; monies required to initiate and sustain new services are not readily available and the co-ordination of diverse services is not easily achieved.

The solution probably lies in refocusing the 'problem' of day services from one that is addressed as a subset of learning disability services to an issue of social inclusion for a marginalized group of people within our society. This means engaging with a range of statutory and non-statutory agencies across many different sectors rather than relying solely on health and social services to deliver new forms of services. Nonetheless for the foreseeable future, they will continue to have lead responsibility for this client group as they negotiate with and support other agencies in undertaking new roles.

The chapter is divided into five main sections.

Section 1 examines Day Centre provision;

Section 2 focuses on Further Education;

Section 3 outlines options for Vocational training and Supported Employment

Section 4 reviews research into Leisure and Friendships.

Section 5 considers new service strategies, with particular emphasis on the transition period of 14 to 25 years.

Section 1. Day Centres

Day centres are the bedrock of day service provision in Northern Ireland as elsewhere in these islands although this was not always so. In December 1962, over 1,800 persons were resident as 'special care' patients in Hospitals whereas 833 persons – children and adults – were enrolled in 19 day schools and occupation centres (Scally and McKay, 1964). By 1982, the balance had shifted as the number of places in day centres rose to over 2,000 and ten years later in 1992, this had increased to over 2,800 places with some 3,100 people receiving a service (DHSS, 1995).

In 2002, an estimated 4,000 persons are registered with day centres/training centres and workshops (DHSS&PS, 2002: NB with correction for an over count in one Trust). This represents around 70-75% of persons aged 20 to 64 years living with family carers or in their own accommodation (McConkey and colleagues, 2000, 2002, 2003a, 2003b).

However the number of places provided in centres is lower because a proportion of persons attend centres on a part-time basis. In the financial year 2001/2002, day centres cost £24.5 million.

Comparable figures for Scotland in 1998 were 8,300 attenders at a cost of £53 million (Scottish Executive, 2000) and for England over 60,000 attended local authority day centres at a cost of around £240 million (Department of Health, 2001).

Although these figures may not be strictly comparable, they do suggest that the per annum cost for each person attending a day centre in Northern Ireland is around £6,100 whereas in Scotland it is £6,400 and in England it is £4,000 (NB the lower figure for England may reflect the net cost after charges have been deducted.)

The data from the three countries suggests that there are more people attending day centres in Northern Ireland (23.5 per 10,000 of total population) than in Scotland (15.1 per 10,000) and England (12.0 per 10,000). The lower figures for Scotland and England may reflect greater numbers of people in other forms of provision or not in receipt of any other services.

In the Republic of Ireland around 6,700 people living with family carers or in community accommodation attend some form of day provision. This is equivalent to 17.2 people 10,000 total population with an average cost of around €9,000 (£6,100).

Who attends day centres?

A total of 77 day centres were identified during the Northern Ireland Review of Day services (McConkey, 2004 a). A postal questionnaire sent to the managers yielded 48 replies (62% response).

The median number of people registered with the centres was 44 but the range was from 2 to 170. The median age of attendees was 40 years (range 16 to 87 years). The centres served a diverse clientele. For example, each centre had a median of 8 people with severe challenging behaviours ; 6 persons with profound disabilities; 3 wheelchair-users, 1 person with autism and 1 with dementia. In addition 25% of centres had at least one person who was technologically dependent (one centre had six persons.)

Research conducted in Foyle HSS Trust (2000) contrasting centre attenders in 1994 and 1999, found an increased number of people with medium and high dependency allied with challenging behaviours. One Derry centre in particular had transformed into a 'high dependence care facility' as more able clients had moved on to vocational training, supported employment and outreach centres. This finding is common throughout these islands and has led some to argue that centre attendance in the future should be restricted to those individuals in need of 'social care'.

Demand for places

The number of people in Northern Ireland seeking places in day centres continues to exceed the vacancies that arise through retirements or deaths.

An estimated 180 children with severe and profound learning disabilities leave school each year – 900 in the coming five years (McConkey, Spollen and Jamison, 2003). If all were to be accommodated in day centres; this would require an increase of around 20% in the number of places and an additional revenue cost of £5.5 million. To date the main way in which this pressure has been responded to is by increasing the number of part-time placements.

More attention need to be given to the alternative options. For example in one HSS Trust, of the 49 school-leavers over a five year period; 80% were estimated by their teachers to require day care (Sperrin Lakeland HSS Trust, 2000). By contrast nearly half of the parents (47%) in a Belfast survey would like their special school-leaver to get a job and another 8% thought a mix of activities would suit their son or daughter best. Only one third felt a daycentre place was required (Smyth and McConkey, 2003).

Functions of centres

In the United Kingdom the form and functions of day centres have changed over the years. Originally conceived as 'occupation centres' with an emphasis on sheltered work, they gradually transformed during the 1960s into Adult Training Centres with a focus on independence and skill development through to Social Education Centres in 1980s when leisure and recreation came to the fore until the present day when the vogue is for Resource and Activity Centres with the aim of supporting outreach into the community (Simons and Watson, 1999a).

The N.I. survey of day centres (McConkey, 2004a) identified the different functions that centres attempted to fulfil. The following functions were those that at least two-thirds of managers reported as meeting for most of their clients (the percentage of centres is given in brackets: N=48).

- Provide opportunities to have fun and enjoyment (94%).
- Keep an eye on people who may be vulnerable to neglect or abuse (92%)
- Give people a break from being at home (89%).
- Provide opportunities to socialise, make friends, develop relationships (88%).
- Provide personal care in safe and respectful ways (85%).
- Encourage social inclusion and use of community facilities (76%).
- Encourage self or group advocacy. Promote positive self-image (69%)
- Stimulate the person through senses, creative arts (69%).
- Provide a resource base for health and dental checks (66%)

Surprisingly fewer centres rated the functions of providing educational opportunities, vocational training and employment as being met for most of their clients. This suggests some differentiation of the primary aims of day centres away from the functions of skill development and training that had featured more strongly in the past.

Several reasons could be advanced for this: the changing needs of people attending centres; the growth of alternative options for providing these functions such as FE Colleges and the advancing 'social care' ethos that permeates day care for all client groups.

However there was variation among centres in the functions they identified and the extent to which they met them for their attenders. Likewise, Beyer et al (1994) in a survey of Welsh centres found wide variations in what people actually did in centres even within the same local authority. It appeared that personalities and precedents rather than a coherent service philosophy determined what was offered to clients.

The views of people attending centres

Recent reviews of day services in Northern Ireland have ascertained the views of people with disabilities through individual and small group interviews, and consultations events with presentations being given by Day Centre Committee members. Among the aspects most valued are opportunities to meet friends, different activities both in and outside the centres; work placements and having a job, getting money (many centres make payments of up to £4 per week); the support and friendships of staff in the centres and a chance of becoming more independent.

They identified many improvements including, better transport arrangements, more staff, more training placements and work opportunities, more leisure activities especially in the evenings and at weekends, an end to bullying within centres, more advocacy and better 'wages' (McConkey, 2004a).

Reconfiguring centres

One particular constraint in redefining the function of centres is the actual building used. Often these were not built for the purpose they are now called on to serve nor are they located in settings that easily foster community integration.

Large centres draw people from a wide geographical area which makes it difficult for people to maintain contacts with their centre friends at evenings and weekends. However the primary concern has been with the time people spent travelling to/from centres (especially in rural areas). In NI, only 20% of centres were able to transport most of their clients from home to the centre in 30 minutes or less. Furthermore transport costs are estimated to absorb up to 25% of the centre's revenues costs plus the added capital costs.

A favoured solution to the transport issue has been the development of smaller and more local 'satellite units'. In Wales, 39% of centres had developed such units by the mid 1990s (Felce et al, 1998) and there is evidence of this happening also in Northern Ireland (McConkey, 2004a). The theory is that these units will also enable people to access community resources more easily although has yet there has been limited evaluation of their effectiveness on so doing. Felce et al (1998) found little evidence of increased individualisation of the service or difference in activities undertaken within smaller units. A major reason for this, is that staff perpetuated their familiar work routines into these new settings rather than changing to accord with the new opportunities.

A related development has been the idea of a 'drop-in' centre which is controlled more by users who decide on the activities and they are responsible for managing the centre with the support of facilitators (McIntosh and Whittaker, 1998).

Centre closures

A more radical view has been to promote the closure of all day centres along similar lines to the resettlement programmes from institutional care and to replace them with individually-based, "services without walls". However few, if any authorities have taken this step and it does not appear to have widespread support. For example Mencap (2000) argued that *"there will always be a place for building-based services – even if more of these are resource centres and most activities take place elsewhere"*(p.12).

Rather the emphasis has been on defining more clearly the clientele that is served by day centres and the specific services provided by the Centre. The Mental Health Foundation (1996) proposed that centres "*should be encouraged to evolve from within, developing services tailored to the individual needs of their users…. Those who attend should be offered an individual contract with the centre, setting out the nature of the services they will receive, to be reviewed regularly.*" (p. 39).

Changing Centres

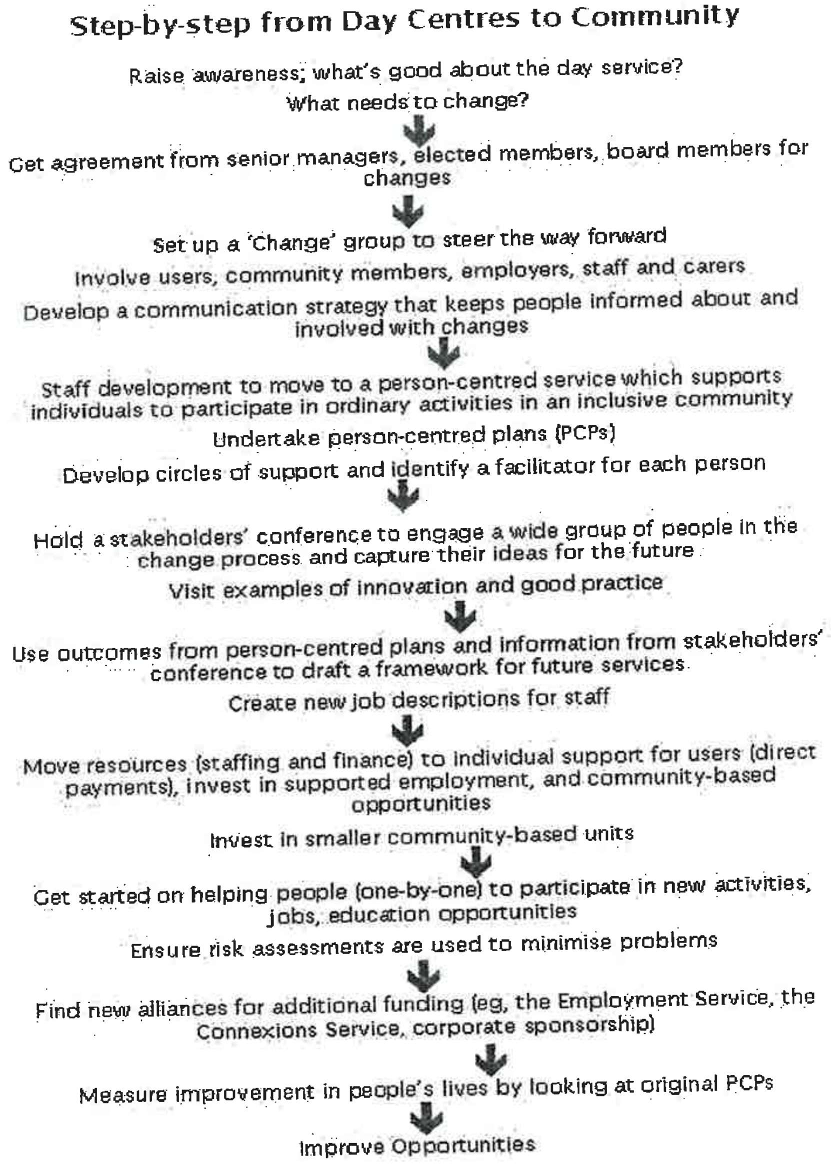
McIntosh (2002) directed a five-year 'Changing Days' development programme based in the King's Fund Centre and involving nine sites throughout the UK. The key aim was to improve people's day opportunities and a core element was re-formulating the form and function of day centres. A major stumbling block was the culture within statutory services. Among the main issues identified were:

- Ten years of budget cuts and constraints.
- Little input from care management in many day centres and a sense that some care management services were acting as a rationing service.
- Financial issues were complex. Few managers had a good understanding of how to manage financial changes and shift funding to the community and to individualised support.
- Managers overwhelmingly felt that they had no guarantee that capital raised in selling a day centre would come back to the learning disabilities service. This proved to be a barrier in itself.
- The day centre culture was busy and friendly but most of the energy of staff went into maintaining existing routines. It was exceptional to see examples of planning which moved towards individualised lifestyles.
- The friendly environment of many day centres acted as deterrent for some staff to look outwards to the community".

From experiences gained in effecting changes, the research identified key stages in moving from centres to community. These are summarised in the Figure overleaf.

McIntosh (2002) concluded that: "*All of these changes ask service users, staff, and parents to be energetic and committed in finding new solutions and to be more creative in the use of public funding…. The challenge remains to show that individual by individual, and community by community people can receive the right support, retain the best of the past, and have new positive experiences in the community*".

Figure: Stages in changing from Day Centres to Communities (McIntosh, 2002)



Step-by-step from Day Centres to Community

Raise awareness; what's good about the day service?
What needs to change?

↓

Get agreement from senior managers, elected members, board members for changes

↓

Set up a 'Change' group to steer the way forward
Involve users, community members, employers, staff and carers
Develop a communication strategy that keeps people informed about and involved with changes

↓

Staff development to move to a person-centred service which supports individuals to participate in ordinary activities in an inclusive community
Undertake person-centred plans (PCPs)
Develop circles of support and identify a facilitator for each person

↓

Hold a stakeholders' conference to engage a wide group of people in the change process and capture their ideas for the future
Visit examples of innovation and good practice

↓

Use outcomes from person-centred plans and information from stakeholders' conference to draft a framework for future services
Create new job descriptions for staff

↓

Move resources (staffing and finance) to individual support for users (direct payments), invest in supported employment, and community-based opportunities
Invest in smaller community-based units

↓

Get started on helping people (one-by-one) to participate in new activities, jobs, education opportunities
Ensure risk assessments are used to minimise problems

↓

Find new alliances for additional funding (eg, the Employment Service, the Connexions Service, corporate sponsorship)

↓

Measure improvement in people's lives by looking at original PCPs

↓

Improve Opportunities

A service for carers?

Day centres are not just for people with a learning disability. A major function is the respite they offer family carers in particular but also the substitute care they offer for people living in residential services. (In Northern Ireland on average 30% of day centre attenders are in some form of residential accommodation). This has led Dowson (1998) to question to closure of centre-based services and Mencap (2000) to argue that "*day centres should only close if there are good places to go to instead*" (p.13).

The implicit contract with carers, is that centres will offer year-long, five-day placements for a specified number of hours per day with transport provided to/from the person's residence. With demand exceeding supply, part-time attendance at centres has become increasingly more common (Mason, 1998). Sometimes service-users attend alternative services (e.g. College or work placements) but others are home-bound. It has proved very difficult to offer carers a guaranteed five-day service all year round in ways other than through attendance at the same day centre. This more than anything, may account for the resilience of the centre-based service model, especially when the views of the person with learning disability are not sought or heard.

This demand is further reinforced by the lack of access that Northern Irish carers have to respite breaks at other times such as evening and weekends (Sines, 1999; McConkey and Adams, 2000).

Variations consultations were held with family carers as part of the NI Review of Day Services (McConkey, 2004) and as part of the day services reviews in two trusts (Foyle, 2000 and Sperrin Lakeland, 2000). They valued the role centres played in helping their relative become more independent, to socialise and to take part in a range of activities. They also found the staff supportive and helpful. However they identified many inadequacies; notably the need for longer opening hours, staff shortages, excessive travelling times to and from centres; improved contact with clinicians, better information and support for carers; work opportunities, wider range of activities and more individualised planning. In sum, the day centre service was not planned to meet the explicit needs or wishes of carers. This is ever more apparent for carers who are in full-time employment and for those caring for a multiply disabled relative. .

Carers of school-leavers expressed concern about the age range of people attending centres and were more willing to explore alternatives such as Colleges and employment (McConkey and Smyth, 2002).

What happens in centres?

A growing body of research has looked at the experience of centre attenders in terms of their level of engagement in activities and the amount of time spent in non-segregated settings.

Levels of engagement appear to vary considerably across centres; from 18% to 92% of clients' time spent in activities within Welsh Centres (Lowe et al, 1991). The main reasons for disengagement tended to be time spent 'waiting' although for people of lower ability, not being allowed or enabled to participate was the most common reason. People with greater support needs spent on average only 12% of their time engaged in activities (Pettifer and Mansell, 1993).

A study of 17 English day centres (mean of 81 places in each) found that on average each person had around 20 hours of timetabled activities; mostly arts and crafts, personal development and sports (Felce et al, 1999). External paid work or voluntary work were marginal activities accounting for only 3% of activities noted. Overall, only 13% of person-hours were organised as individual activities; most time was spent in groups. Users had staff attention for around 16 minutes in each hour and were engaged in activities for 54% of the time but this fell by half in sessions for people with high support needs. The researchers concluded that people with high support needs within typical day centres had only about 5 hours of constructive occupation per week.

The picture is similar in the way centres respond to people with challenging behaviour (Allen and Hill-Tout, 1999). Fewer numbers of these individuals attend the centres than would be expected; suggesting that such people are actively excluded. There was also little evidence of any special planning around the behavioural needs of clients and where plans did exist, they were predominantly reactive in nature.

However levels of engagement for people with additional needs could be boosted when they were given intensive support by centre staff who had been specially trained in these methods (Jones et al, 2001).

Comparisons of engagement levels across different settings are sparse but Kilsby and Beyer (1996) and Bass and Drewett (1997) reported near doubling of engagement levels in supported employment settings compared to day centres.

Although centres have become more outward looking, Beyer et al (1994) reported that two-thirds of person hours were still spent within centres. However even when people use community facilities they may do so as a distinct group, for example in the use of public swimming pools (SSI, 1995) or attend a satellite unit established by the centre but based in a community building.

Although similar data is not available for centres in Northern Ireland, the data presented earlier on the functions which centres serve, does suggest a predominance of a care and leisure ethos. In part this role may have been forced on centres due to resource constraints.

Pressures on Day Services

The main pressures identified by existing centre managers were lack of staffing, lack of access to better resources and equipment; inadequate building and better access to transport (McConkey, 2004). In particular managers noted:

- Services have difficulty in recruiting and retaining staff. Salary levels and grading structures need to be reviewed. There is insufficient staff to cover holidays and sickness. More training is required.
- Journey times to/from centres are too long. More suitable vehicles are required.
- All services have to cope with clients with a wide range of abilities and ages among the clients.
- More funding is required, with employment services emphasising the need for guaranteed long-term funding.
- The majority of respondents felt that incentive payments should continue to be paid by centres although a sizeable minority did feel they should be discontinued.

Diversification of functions

In recent years, there has been a shift away from multi-functional centres. A national survey in the Republic of Ireland (McConkey and Murphy, 1989) identified four types of centres (serving an estimated population of 6,500 people): short-term training centres (18% of all attenders were placed here); long-term training centres for more able clients (18% attenders) ; long-term centres for the full range of clients (42% attenders) and short and long-term centres for people with a mix of learning disabilities and other disabilities (22% of total).

A Welsh survey of day centres (Beyer et al, 1994), identified four 'models' based on the pattern of activities they offered; namely Recreation (mainly arts and crafts and sports); Recreation plus personal development (as before plus personal care and social skills); Employment (focus on work experience and paid employment) and Occupation (mainly contract work). However these models were not linked to particular local authority or size of centres which suggests they are not linked to specific policy initiatives.

Similar conclusions had been reported by Seed (1988) in his study of Scottish Centres. He proposed the way forward should be through the promotion of three types of resource centres: a 'work resource' centre focussed on obtaining paid work for clients; a 'further education' centre that concentrated on developing the skills needed for living more independently in the community and a 'community resource centre' designed to strengthen client's links with people and facilities in their local communities. A consequence of this analysis, is that each model would require distinct staffing, resourcing, curricula, location and management. One centre could not deliver these three models simultaneously.

Seed's tri-partite conceptualisation has been validated by subsequent reviews of policy in day service provision, e.g. by Mencap (2000), Mental Health Foundation (1996) and Department of Health (2001) but with one important difference. Further Education and Employment services are seen to be the responsibility of mainstream services rather than of health and social services which flowed from a new emphasis in Government policy on social inclusion and equal opportunities for people with disabilities.

Conclusions

The existing model of day centre provision needs to be radically reviewed.

A major challenge for Health & Social Services has become one of persuading and ensuring that mainstream agencies accept their responsibilities with regard to ordinary needs of this client groups. Additionally mechanisms need to be devised to co-ordinate the various services that each individual receives.

When and if these developments happen, it will be somewhat easier to re-define the functions of day centres provided by social services but meantime centres will probably have to struggle with trying to meet too many diverse aims for too many people with a wide range of needs and aspirations.

Section 2. Further Education

The inclusion of adults with a learning disability in the further and continuing education sector dates back to the 1970s in Great Britain and from 1982 in Northern Ireland. However it was not until the 1990s that this provision became more widespread. In Wales the number of places doubled in the period 1983-1995 (Perry et al 1998). This has been attributed to changed management and funding arrangements for FE Colleges that took place in Great Britain which increased the autonomy of colleges and provided financial incentives for the enrolment of special needs students (Simons and Watson, 1999a). Similar arrangements are now in place in Northern Ireland.

Although the changes were broadly positive a review undertaken by Macadam and Sutcliffe (1999) identified a number of shortcomings. The booming provision for people with moderate learning disabilities tended to squeeze out places for people with more severe disabilities, which in any case was very limited. The curriculum had narrowed to focus on literacy and numeracy skills and vocational courses. The increased emphasis on nationally accredited courses meant fewer courses that specifically met the needs of people with a learning disability. Much of the FE provision consisted of special classes and courses rather than including people with a learning disability in mainstream courses. This consequently limits the opportunities for social inclusion.

A major shortcoming has been the lack of evaluation of the value of these courses to the learners and of systems for inspecting the quality of provision on offer. Two further concerns are the lack of progression from FE provision and the failure to instigate effective cross-agency collaboration involving education (Simons and Watson, 1999).

A review of FE provision in Northern Ireland for students with a learning disability (DHFET, 2000) found significant variations across Colleges in the number of these students enrolled as a proportion of the student body – 0.4% to 18.5%. However the average level of enrolments (4.1%) was lower than the mapped incidence for England (5.7%). The differences in full-time enrolments was even more marked – 11% of all students with a learning disability in N. Ireland were enrolled on full-time courses, whereas in England the comparable percentage was 45%.

The report concluded that: *"a formal and coherent approach to the principles of .. inclusiveness is underdeveloped in the FE Sector in terms of policy, planning, management, resourcing and identification of unmet need"* (p ii).

There are however good examples of innovative practice taking place in Northern Irish Colleges for pupils with severe learning disabilities (e.g. McConkey, McCallum and Patterson, 1999). The curriculum of one fulltime course covered adult basic education, the use of information technology, independent travel, health promotion, work training and a work experience placement. An evaluation of the course at the end of the second year involving the 17 students enrolled and their families, found that all but one had coped with the College environment; the course had increased students' confidence; the student's learning had been accredited, the work placements were particularly valued; and the parent's initial reluctance had dissipated. Ongoing issues included transport from home to College; the need for ongoing links with the Special School; developments in the curriculum; and the student's inclusion in other College activities and post-course provision.

A consultation conducted by Mencap NI (2003) in their Northern District into FE provision noted the range of courses being taken on a part-time basis by people with a learning disability: cookery and food preparation, hairdressing, office skills, first aid courses, adult literacy, art and craft, gardening, personal grooming, music and physical education. They commented on a reliance on day centre transport for getting people to and from college and that active steps need to be taken by colleges to encourage and promote the inclusion of people with a learning disability in all aspects of student life. Also in some areas the absence of a local college meant that people with a learning disability did not have the opportunity to experience student life in a college.

People who have taken courses at colleges generally speak favourably of their experiences both in terms of the subjects studies and achieved attained but also in terms of their social and personal development (e.g. Harrison, 1996; Skill NI, 2000). However a more structured and organised system is needed within Colleges to support their learning with greater attention being paid to their individual aims and aspirations and planning the learning process in association of students. They also valued having someone in colleges whose help they could enlist in representing their requirements (Skill NI, 2000). The appointment of Special Educational Needs Co-ordinators within Colleges could go some way to meeting these needs.

A consultation conducted by a group of young people with disabilities (Educable, 2000) concluded that the low expectations of teachers and often parents had left them unprepared for life after school. They identified the need for independence training to be more practical and started earlier in life; for more informal education opportunities to promote confidence building, self-esteem and assertiveness and for the non-academic learning to be accredited in National Awards.

Conclusions

There is great scope for further developments within the FE sector in Northern Ireland even to bring it in line with practice in Great Britain. However this will require major commitment from colleges to address adequately the needs of this group and for them to forge partnerships with other agencies in these endeavours.

A Special Educational Needs and Disability Order for Northern Ireland should come into place in 2005. If it follows English legislation it should give people with disabilities new rights in adult and community education, further education, higher education institutions and youth service provision. Likewise the Disability Discrimination Act has been extended recently to further and higher education.

Nonetheless further education is another step in life's journey but in itself is not the end. A critical issue is what happens when College courses are completed? The need to prepare young people with disabilities to take their place in the workforce must be to the fore throughout their education (Monteith and Sneddon, 1999).

Section 3: Vocational Training and Supported Employment

Although in past years work was always an option for people with a learning disability, this was largely done in the context of sheltered settings with an emphasis on contract work that typically involved boring, repetitive tasks with little monetary reward for the so-called 'workers'.

However the advent of supported employment from North America, with its slogan 'real jobs for real pay', has opened up new possibilities for people who previously were deemed unemployable in the open job markets.

Supported employment is based on the principle of 'place and train' (Beyer and Kilsby, 1997; Anderson, 1998). Job opportunities are found for the person in line with their talents and interests. He or she is then trained on-the-job by a 'job coach' who also adjusts the working environment if necessary and enlists the assistance of co-workers. The job coach gradually fades out but remains in contact with employers should any problems arise.

This approach is directly counter to the 'readiness model' which aims to prepare people for work through special training programmes; a model that had dominated in the field of disability nationally and internationally. However a low proportion of trainees actually obtained paid employment in the open labour market (Beyer et al, 1994).

There has been considerable growth in supported employment in the UK over the last decade with some 200 agencies in 1995 who were supporting in excess of 5,000 people and the numbers were growing.

In the Irish Republic nearly 1,000 persons with earning disabilities are in supported employment projects which recently received a major boost when the Government 'mainstreamed' these services into the *FAS*; the agency for training and employment and provided around €4 million per annum to support schemes provided mainly by voluntary sector consortia.

At present, the NI Union of Supported Employment has over 15 non-statutory agencies in its membership plus many other day centres are involved in this work.

In the main, these supported employment services have focused on clients with mild and moderate disabilities although there is some evidence that people with severe disabilities and challenging behaviours can benefit also (Martin et al, 1999).

There is also growing evidence of the cost-benefits of these services (Beyer et al, 1996) with high levels of user satisfaction. However one of the main disincentives has been the impact of earnings on social security benefits paid to people with disabilities and their families (Simons, 1998a).

To date the main funders of supported employment services in Great Britain have been social services and health authorities although in Northern Ireland and the Republic of Ireland, European monies have provided the bulk of the costs. However these funds are not guaranteed in the longer term. Also recent experience in the Republic of Ireland has shown the difficulties that can arise in ensuring that supported employment services fully meet the needs of people with a learning disability when they are provided through mainstream training and employment agencies who measure success in terms of the number of people placed in employment within specific time periods.

However there is growing evidence in Northern Ireland as well as elsewhere that young people leaving school and their parents aspire to having paid work. Nearly 50% of parents and over 90% of young people in a Belfast survey mentioned having some form of paid work as their preferred activity after leaving school (Smyth and McConkey, 2003).. Many of the young people appeared to be influenced by the work experience placements they had undertaken either in school, FE College or the day centres. The most commonly mentioned jobs were in shops (7) office work and computers (7) and catering/cooking (5).

Likewise a survey of 275 persons attending three, day centres in Belfast suggested that upwards of one-third aspired to having a job and their key-workers thought that one in five would be able to hold down a job (McConkey and Mezza, 2000). These proportions were higher among those persons who had previous work experience placements and/or who attended courses at Further Education Colleges. Centre staff viewed poor concentration, communication skills and motivation as the most common obstacles to obtaining paid work. The main benefits to the individuals they saw were increased self-esteem, independence and confidence.

Other training and employment models

In addition to supported employment, a number of other approaches have been developed to better prepare people for employment and to give realistic work experiences. McGrath (1995) classified them as follows:

Vocational training: These provide time-limited courses linked to nationally accredited awards such as NVQs. Often they are linked with unpaid work experience ideally in a range of jobs so that people have 'tasters' of what work is like and whether it matches their expectations.

Social Enterprises and Social Firms: These have been created specifically to give employment for people with disabilities. They pursue a market-orientated production of goods and services on a commercial basis. Employees are paid at least up to maximum allowed by social security benefits. Opportunities for work experiences can also be offered and some employees may move into supported employment in comparable businesses.

Supported Volunteering: The concept of people with a learning disability acting as volunteer workers to help other people is largely underdeveloped. However there is growing experience of their aptitude and competence in these tasks which to date have included childcare; home helps and assisting in residential care settings.

In sum, opportunities to work and the prospect of paid employment can be a reality for sizeable numbers of people with a learning disability if they receive appropriate training and support.

Experiences of employment-related schemes in Northern Ireland

The NI Review of Day Services (McConkey, 2004a) identified 31 employment related schemes; 17 of which responded to the questionnaire. In addition to vocational training, work placements and supported employment initiatives, a wide range of work opportunities and social firms were reported including recycling schemes, horticulture, café and catering, pottery and business centres.

Unlike day centres, these services identified only two main functions they fulfilled for most of their clients: namely the provision of vocational training, career education, work experiences and supported employment (80% mentioned this) and to provide educational opportunities in social skills, literacy and numeracy (69%).

The median number of people registered with the schemes was 44 (similar to day centres) but the median age was lower – 30 years (range 16 to 67 years). Each service had a median of 3 persons with autism and 1.5 persons with severe challenging behaviours. Typically these services had no persons with profound disabilities; or who were wheelchair users or had signs of dementia although some of the services had people who fell into each of these categories. The majority of people lived with family carers.

The main improvements that managers of these services wanted were: more long-term funding; more opportunities for work/work placements; improvements to the benefit system to take away the disincentives to obtaining paid employment; more staff and better staff training.

There has been limited evaluation of vocational training initiatives in Northern Ireland. Taylor, McGilloway and Donnelly (2001) evaluated four schemes provided by various agencies under the V.O.T.E initiative with over 70 beneficiaries with disabilities. They concluded that the schemes had achieve significant success in terms of improving trainee's employment prospects although the numbers actually gaining paid employment were small. They concluded that future services and projects should focus on the identification of suitable types of training, work placements and employment; the selection of appropriate candidates for different types of schemes, paths or settings; ways of supporting employers to adapt working practices and 'culture' and to support mechanisms that will enable more young adults with disabilities to cross the important step from improved qualifications and useful work placements to paid employment.

Evaluations of supported employment schemes have likewise documented the benefits to trainees; the approval of family carers and the support given by employers and co-workers (Anderson, 1999; McConkey, 2000: McConkey; Mezza and Wilson, 2000). However few of the trainees in these schemes had made the transition from training placement to paid work. Among the possible reasons are a reluctance by family carers to move off benefits, the type of placements selected not leading to paid work; the employer's unwillingness to make payments and the longer time required by these clients to make the transition from training to work.

Even so, a growing number of people with a learning disability are reported to be in some form of paid work, albeit individuals who are more capable. In the EHSSB and SHSSB areas, 10% and 8% of people with a learning disability were reported to be in paid employment; mostly part-time work; a figure that is broadly comparable with England and Wales.

Consultations with people who had experienced work highlighted how much they valued having a job and the benefits it brought not just financially but in terms of social inclusion, self-esteem and the opportunity to become a valued member of the workforce (NIUSE, 2003)

Future Prospects

These recent experiences allied to changes in legislation, such as the Disability Discrimination Act and Section 75 of the Northern Ireland Act, has resulted in increased commitments towards widening employment opportunities for people with a learning disability.

The Scottish Review of learning disabilities concluded that: "*Many people with disabilities want a decent job. They want to get on in life and have friends at work. The*

Scottish Executive's social inclusion strategy ranks having a job high in the list of measures to help people to be included in society. Employment has, so far, rarely been an option for people with learning disabilities. If they are to be usefully included in society, that has to change." (Scottish Executive, 2001: p. 58).

Likewise the English Review placed particular emphasis on creating more opportunities for paid work as their unemployment rates are greater than for people with other disabilities. The target set was "*to increase the employment rate of people with learning disabilities and reduce the difference between their employment rates and the overall employment rate of disabled people"* (Department of Health, 2001: p. 85).

In Northern Ireland this will necessitate closer working relationships between Health and Social Services with the Department of Employment and Learning than has hitherto been the case.

Conclusions

Many people with a learning disability aspire to having a job and increasing numbers of parents hold this aspiration for their teenage sons and daughters.

A range of vocational training courses leading to accredited awards have been developed tailored to the needs of this client group.

Various special initiatives, notably supported employment, have proved successful in creating work placements and paid employment.

Greater commitment is required from the Department of Employment and Learning and closer working relationships need to be established with Health and Social Services agencies.

Section 4. Leisure and Friendships

Many people with a learning disability live lonely lives. Most of their free time is spent in home-based pursuits such as watching television and listening to music with few friends of their own age.

Smyth and McConkey (2003) interviewed the parents of over 50 school-leavers from two special schools for pupils with severe learning difficulties in Northern Ireland. Three in five of the young people (58%) were reported to have no friends of their own. Of those reported to have friends (16 students in all), 12 were from the same school or centre as the young person attended although two of these also lived in the neighbourhood of the young person. Only one young person had a weekly meeting with her school/centre friends outside of the school setting; more often it was fortnightly (3), monthly (4) or occasionally (4).

Four students were reported to have non-disabled friends from the neighbourhood (11%) although only one person met his friend weekly usually in clubs or pubs.

In all 90% of parents would like their son or daughter to be more involved with friends of their own age and they mentioned the need for more clubs (10) and for more sports and leisure activities (6).

A similar picture emerges for adult persons (McConkey and McCullough, 2002). Over two in five people report that they have no friends outside of the day centre they attended and four was the most that anyone reported. The most common activities undertaken with friends were going to discos and social clubs but most of these were organised specifically for people with a learning disability, such as Gateway Clubs.

A study of 65 persons resettled from a long stay Hospital in Northern Ireland into nursing home and residential care (McConkey et al, 2000) found that only 14 people (21%) had regular or frequent contact with friends outside of their residence. This included contact with people in day centres. Only five people were reported to meet their friends away from the centres; through visits to the residence (4) or going out with them socially (2) or for shopping (1).

Overall, the mean number of different leisure activities residents had engaged in during the past four weeks was 5.6 However people living in nursing homes had a significantly lower mean score (3.1 activities) than those in residential (mean score 5.8) or community homes (7.4 activities). A similar pattern was reported by Emerson et al (2000) when comparing people living in residential campus settings and those living in dispersed community housing.

Overall people with a learning disability tend to lead more sedentary lifestyles than the general population and engage in significantly less than the minimum levels of physical activity recommended by the Department of Health (Messent et al, 1998). Levels of obesity appear to be rising among adults with a learning disability in Northern Ireland (Marshall et al, 2003).

The views of people with a learning disability and carers

People with a learning disability often express dissatisfaction with their community, recreation and leisure activities (Sands and Kozleski, 1994). They mention in particular the need for more evening and weekend activities and greater opportunities to take part in community events. Among the obstacles they currently experience are the lack of public transport and the prohibitive costs of taxis, problems with physical access to premises such as cinemas, night clubs, bars and restaurants and the lack of a companion – befriender – to accompany them (Educable, 2000).

A study in the SHSSB area (Gordon, 2003) found that proportionately fewer young people with disabilities attended youth clubs, youth organisations and participated in summer schemes. The attitudes and practices of youth workers and leaders may be a major factor in this. It recommended better training for staff and increased resources provided by Department of Education.

Many family carers are also concerned about the lack of leisure opportunities (McConkey, 2004a). Among the suggestions they made were:

- Drop in centres and more social clubs
- Weekend or short breaks away
- Befriending schemes with long term commitments
- Education of the general public about learning disabilities
- Community Access/Support Workers to allow individuals to attend events/concerts rather than depending on their ageing parents/carers to take them
- Day centre facilities utilised in the evenings

Existing provision

Relatively little monies have been expended by social services in promoting the social and leisure lives of people with a learning disability. Often this has been left to charitable groups (often led by parents and relatives) and they continue to be the main provider of leisure opportunities outside working hours with a heavy reliance on volunteers.

The NI Review of Day services identified over 100 groups and schemes throughout Northern Ireland. Based on responses from 24 leaders, the median number of people registered with each scheme was 51 persons (range 6 to 409) with a median age of 30 years (range for 3 to 6 years). Most lived with family carers. Their primary functions were to:

- Encourage social inclusion and use of community facilities (96% mentioned this).
- Provide opportunities to socialise, make friends, develop relationships (91%).
- Provide opportunities to have fun and enjoyment (91%).
- Give people a break from being at home (86%).

The main improvements they felt were necessary included more funding, more staff and volunteers, better transport, more support from statutory agencies and better public awareness of disabilities.

However critics have suggested that special clubs perpetuates the segregation of people with a learning disability. Latterly a more tolerant approach has emerged largely based on the wishes of people to have friends who were also disabled (McConkey, 2004a). Intimate friendships are also more likely to be formed from within these networks.

Befrienders

The main service innovations in this area has revolved around the concept of befrienders; ideally a person of similar age, background and interests recruited to share some of their leisure time with a chosen partner. A Northern Irish survey identified this as the fifth most popular form of voluntary activity with an estimated 80,000 people involved across all client groups (Holloway and Mawhinney, 2002).

A number of dedicated befriending schemes have been set up by a range of agencies in Northern Ireland mostly in the non-statutory sector although as yet there has been no evaluation undertaken of their impact and sustainability.

A variant is the use of adult family placement schemes in which people with disabilities are placed with a carefully selected family for short-breaks. This has evolved out of family-based short breaks for children although to date fewer schemes involve adult persons and rarely have been they targeted at older carers whose need for breaks is well-attested.

The experiences of 25 carers, aged 55 years and over, of people with intellectual disabilities using one of two placement schemes in Northern Ireland were studied along with a further 20 carers who had been recommended for these schemes by their social worker (McConkey et al, 2004). Semi-structured, individual interviews were used to obtain the views of carers, people with intellectual disabilities and placement providers.

The placement schemes were very favourably received. All the carers wished to continue their involvement and most of the older carers not using such schemes expressed an interest in participating. The main benefit offered to carers was the chance of a break but they also valued the relationship they had built with the placement provider. Individuals with the disability reported that they had greater opportunities to participate in a range of activities while on placements.

The majority of placement providers were recruited from the care sector and many had previous experience of people with intellectual disabilities. Overall they were very satisfied with the way the schemes operated. The main complaint was the low level of payments.

The study identified a number of key issues affecting the further development of such services, notably recruitment of male providers, training and registration issues of placement providers and the difficulty in meeting the needs of multiply disabled persons who require special equipment.

However befriending schemes do have some potential drawbacks. The matching of 'friends' is often done by a professional worker or scheme coordinator; hence the person with a learning disability has very limited scope for choosing and developing their own friendships. The 'friendship' that develops runs the risk of being artificial in the sense that the able-bodied person is invariably cast in the role of helper and supervisor. Through time this can place quite a strain on the relationship. If the able-bodied person is no longer able or willing to continue, there is the added problem of finding a replacement while dealing with possible feelings of disappointment and loss in the person left behind.

Another approach attracting much interest recently is that of creating 'circles of support' or 'circles of friends' (Neville, 1996). There is no prescription for the form and format these take, as they will be guided very much by the wishes and needs of the person with learning disability as identified in their person-centred plan. That said there are some common strands in such circles.

They might include family members – siblings, cousins, aunts and uncles; neighbours and acquaintances; co-workers for people in work settings; members of clubs, churches and such like who know the person. The circle deliberately does NOT have professional workers as members although they can have a key role as facilitators or 'go-betweens' in starting the circles.

The depth of friendship will vary across the members of the circle. Some may be prepared to be intimately involved; others will continue as acquaintances but they will be better informed than previously. The circle can support people in educational, employment as well as leisure settings.

Circles Network – a UK-wide organisation – established a Northern Ireland Office in 2000 with charity monies to promote circles of support.

This idea can find expression in other ways. For example Key Ring is a Housing provider for people with a learning disability that works by building up mutually supportive networks among the tenants living within a geographical area as well as linking them into the communities where they live (Simons, 1998b). Likewise new forms of day provision often operate on the basis of creating social networks for their clients by slotting them into educational, employment and recreational opportunities in the community (Towell, 2000). As yet, there have been few formal evaluations of these networks as to whether they fulfil their promise.

Conclusions

The quality of people's lives can be enhanced considerably through social networks and active participation in community life. A growing appreciation of this fact will hopefully provide a much needed spur for greater attention and energy being devoted to making this a reality for more people with a learning disability.

Ironically much more resources are expended on treating the possible consequences of social isolation –such as challenging behaviours and depression – rather than investing in preventative actions. However new strategies will be required as existing provision has demonstrably failed to produce these improved quality of life outcomes.

Section 5. Transitions from school to adult services

A recurring theme in recent British policy has been the need for joint commissioning of services across health and social services. To a large extent this stemmed from the twin sources of funding that have traditionally underpinned service delivery in Great Britain that does not apply in Northern Ireland. However this issue has arguably overshadowed a more complex agenda that is equally applicable to Northern Ireland; namely that of joint commissioning of services with other agencies, notably, education, training and employment services, and community leisure services. This theme will be developed more fully in Chapter 10 but it must also feature in any review of transitions from school to adult services.

Transition from school to adult services

The transition process has been defined as "*a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in post-secondary education, maintaining a home, becoming appropriately involved in the community and experiencing satisfactory personal and social relationships*" (Dunn, 1996). It is generally taken to cover the age range from 14 to 25 years of age.

Four dimensions have been identified in the transition (OECD, 1986); the move into employment and productive activity; the growth of personal autonomy and independent living; social interaction and community participation and the taking on of adult roles within the family; including marriage and parenthood.

Past research in these islands and elsewhere has focussed mainly on young people with physical and sensorial disabilities (Hirst and Baldwin, 1994; Monteith and Sneddon, 1999). The findings suggest that these young people are less likely than their non-disabled peers to be in paid work and to be living independently of their parents. They also had limited social lives with greater reliance on their families for leisure pursuits.

Although fewer studies have focussed on older teenagers with severe learning difficulties, those that have done so, paint a similar picture (McConkey, 1989; Redmond, 1996) with parents having to juggle their aspirations for a 'normal' life with a realistic appraisal of their offspring's needs and their vulnerability (Heyman and Huckle, 1993). Equally the views of these young people have not been sought by researchers although the difficulties in doing this should not be underestimated (Stalker, 1998).

However within services, transitions has been interpreted more narrowly as the move from schools to adult learning disability services. This has attracted a great deal of criticism from family carers in particular who point to a striking contrast between the services available to them and their children with the lack of options available after school. Mencap's (1991) conclusions of a decade ago are still echoed in parent's comments today: "*Young people (leaving schools) were switching from five days a week of planned and structured activity based on individual assessment to a slot (sometimes part-time) in a service not designed for them and not leading anywhere*" (p.3).

Studies in England (Ward et al, 2003) and in Northern Ireland (Monteith and Sneddon, 1999, McConkey and Smyth, 2001) have documented the various difficulties that families and young people encounter during the transition years. These include lack of transition planning (despite the legal obligations to do this under the Code Practice for

Special Educational Needs under the Education (NI) Order: 1996), lack of post-school alternatives, dearth of employment and leisure options, and the need for increased respite breaks for carers.

Two main improvements have been proposed for the transition stage (Department of Health, 2001). These are being implemented in England and Wales (as well as in other countries) and preliminary schemes are operational in Northern Ireland. The NI Review of Day Services, drawing on a wide range of professional expertise and carers' views, recommended that:

1. Education, Dept. of Employment and Learning, and Social Services need to take joint responsibility for transition planning and arrangements for young people aged 14 to 25 years. Local co-ordinating committees should be in place in each trust area and joint funding should be in place for transition services. Non-statutory services can have a major role to play as the lead provider agency (McConkey and Mezza, 2000).
2. There needs to be a designated transition officer for each person in transition (independent from school and social service personnel). This is similar to the proposed Connexions Service in England and Wales and it has been or is about to operate in various parts of Northern Ireland. The funding for these posts must be assured and not linked to short-term grants.

In addition, families and young people need to be given information about the range of options that are available – colleges, vocational training, work placements, supported employment, leisure and volunteering as well as attendance at day centres. This should be done through videos, booklets and a programme of visits.

Families, schools and service agencies need to work together in promoting the young person's life skills, notably independent travel, money handling and social skills.

A person-centred transition plan should be developed in association with young person and family. This should cover the individual's interests and needs – therapeutic services, leisure, friendships, education and employment as well as the development of life skills and vocational skills. Greater use should be made of Direct Payments to fund these service packages.

However Ward et. al. (2003) sound a cautionary note based on their English study of over 200 persons in the transition process. They found that whether or not youngsters had received transition planning seemed to make little difference as to what happened to them after school because of the lack of options available, especially in housing and employment opportunities.

Conclusions

Transition planning requires urgent attention in order to meet the changing needs and aspirations of young people and their families.

More effective means must be found for inter-agency planning.

Further research and evaluation is required to identify new service models and determine their outcomes.

Concluding Comment

Chapter 3 documented the development in accommodation options that are available for people with learning while this chapter has noted the changes that are evolving in day opportunities. There are many commonalities; especially the shift from institutional-type provision towards service that reflect ordinary living.

Perhaps the time has come to dispense with the traditional distinction between day and residential services. To a large extent this has been inherited from institutional models of service provision and has no place in modern services that aim to be person-centred, local community based and supportive of the person's choices.

Rather services in the 21st Century will probably consist of various inter-related strands which individuals will access as their needs change. These will include support for family carers, accommodation and supported living arrangements, and specialist assessment and treatment services in addition to those covered by this review. Hence planning for what was previously termed 'day services' must be done within an overall service framework.

References

Allen, D. and Hill-Tout, J. (1999) A day in the life: Day activities for people with intellectual disabilities and challenging behaviour in two English counties. *Journal of Applied Research in Intellectual Disabilities*, 30-45.

Bass, M. and Drewett, R. (1997) *Real work: supported employment for peole with learning difficulties.* University of Sheffield: Joint Unit for Social Services Research.

Beyer, S. and Kilsby. M. (1997). Supported employment in Britain. *Tizard Learning Disability Review*, 2,2, 6-14.

Beyer, S., Kilsby, M. and Lowe, K. (1994) What do ARCs offer in Wales: A survey of Welsh Day Services. *Mental Handicap Research*, 7, 16-40.

Department of Health (2001) *Valuing People: A new strategy for the 21st Century*. London: Department of Health.

DHSS, (1995). *A review of learning disabilities services in Northern Ireland*: Belfast HMSO.

DHSS&PS (2002) *Personal Social Services – Performance Indicators 2002*. Belfast: DHSS&PS

Department of Higher and Further Education and Training (2000) *Participation and provision for students with learning difficulties and/or learning disabilities (SLDD) in the further education sector in Northern Ireland*. Belfast.

Dowson, S. (1998) *Certainties without centres?* London: Values into Action.

Dunn (1996)

Educable (2000) *No choice: No chance: The educational experiences of young people with disabilities*. Belfast: Save the Children and Disability Action.

Emerson, E., Robertson, J.,Gregory, N., et al. (2000) The quality and costs of village communities, residential campuses and community-based residential services for people with learning disabilities. *Tizard Learning Disability Review*, 5, 1, 5-16.

Felce, D., Grant, G. Todd, S. et al, (1998) *Towards a full life*. Oxford: Butterworth Heinemann.

Felce, D., Lowe, K., Perry, J. et al (1999) The quality of residential and day services for adults with intellectual disabilities in eight local authorities in England: Objective data gained in support of a social services inspectorate inspection. *Journal of Applied Research in Intellectual Disabilities*, 12, 273-293.

Foyle HSS Trust (2000) *Review of day care services for adults with learning disabilities.* Londonderry: Foyle HSS Trust.

Gordon, H. (2003) *What about us? An exploration of the physical and attitudinal barriers to youth provision facing young disabled people in the Southern Education and Library Board.* Belfast: Leonard Cheshire NI.

Harrison, J. 1996) Accessing further education: views and experiences of FE students with learning difficulties and/or learning disabilities. *British Journal of Special Education*, 23, 187-196.

Heyman, B. and Huckle, S. (1993) 'Normal' life in a hazardous world: how adults with moderate learning disabilities cope with risks and dangers. *Disability & Society*, 8, 143-160.

Hirst, M. and Baldwin, S. (1994) *Unequal opportunities: Growing up disabled*. London: HMSO.

Holloway, T. and Mawhinney, S. (2002) *Providing support, educing exclusion: The extent, nature and value of volunteer befriending in Northern Ireland.* Belfast: Parxis Care Group.

Jones. E., Felce, D., Lowe, K. et al (2001). Evaluation of the dissemination of active support training and training for trainers. *Journal of Applied Research in Intellectual Disabilities*, 14, 79-99.

Kilsby, M. and Beyer, S. (1996) Engagement and interaction: a comparison between supported employment and day service provision. *Journal of Intellectual Disability Research*, 40, 348-358.

Lowe, K., Beyer, S., Kilsby, M.and Felce, D. (1992) Activities and engagement in day services for people with a mental handicap. *Journal of Intellectual Disability Research*, 36, 489-503.

Macadam, M. and Sutcliffe, J. (1999) *Still a chance to learn?* Leicester, National Institute of Adult Continuing Education.

McConkey, R. (1989) Our young lives: School-leaver's impressions and those of their parents to life at home and their hopes for the future. In R. McConkey and C. Conliffe (eds.) *The Person with Mental Handicap: Preparations for an adult life in the community.* Dublin: St Michael's House.

McConkey, R. (2000) *An evaluation of Project Progress: Creating supported employment opportunities for attenders at day centres.* Belfast: Mencap.

McConkey, R. (2004a) *Pressures, Possibilities and Proposals: Northern Ireland Review of Day Services for People with Learning Disabilities,* Belfast: EHSSB.

McConkey, R. (2004b) Promoting friendships and developing social networks. In G. Grant et al (eds) *Learning disability: a life cycle approach to valuing people.* Milton Keynes: Open University Press/McGraw-Hill.

McConkey, R. & Adams, L. (2000) Do short breaks services for children with learning disabilities match family needs and preferences? *Child: care, health and development*, 26, 429-444

McConkey, R., Mezza, F. and Wilson, J. (2000) *An evaluation of Project Advance: Supported Employment and people with additional needs.* Belfast: Orchardville Society.

McConkey, R. and Mezza, F. (2000) Project Transitions: Developing systems to facilitate students with severe learning difficulties and their families to manage the transition from school to adulthood. Belfast: Orchardville Society.

McConkey, R. and Mezza, F. (2001) The employment aspirations of people with learning disabilities attending day centres. *Journal of Learning Disabilities*, 5, 4, 309-318

McConkey, R., McCallum, J. & Patterson, I. (1999) Further education for pupils with severe learning difficulties. *Reach: Journal of Special Educational Needs in Ireland*, 13 (1), 12-22.

McConkey, R., McConaghie, J., Mezza, F. and Wilson, J. (2003) *Moving on from Muckamore Abbey Hospital: The outcomes and lessons as perceived by people with learning disabilities; their key-workers, care managers and relatives.* Belfast: EHSSB.

McConkey, R., McConaghie, J., Roberts. P. and King, D. (2004) Family Placement Schemes for adult persons with intellectual disabilities living with elderly carers. *Journal of Learning Disabilities* (in press).

McConkey, R. and McCullough, J. (2002) *An Evaluation of the Opening Doors Project: Leisure activities and friendships with adults who have learning disabilities.* Belfast: Edgcumbe Parents and Friends

McConkey, R., Spollen, M. and Jamison, J. (2003) *Administrative prevalence of learning disability in Northern Ireland.* Belfast: DHSS&PS

McConkey, R. and Smyth, M. (2001) Reflections of parents and students with severe learning difficulties on their special schooling and the transition to post-school provision. *Journal of Research in Special Educational Needs, 1, 3 (electronic journal).*

McConkey, R. and Murphy, R. (1989) A national survey of centres and workshops for adult persons with mental handicap. In R.McConkey and C. Conliffe (eds.) *The person with mental handicap: Preparation for an adult life in the community.* Belfast: ICPD/.

McGrath, M .(1995) Employment focussed day services in Wales, *Llias,* 37, Summer, 6-9.

McIntosh, B. (2002) *The Strategies for Change Project : Modernising Day Services - Lessons Learnt In The Changing Days Programme.* London: King's Fund Centre

McIntosh, B. and Whittaker, A. (1998). *Days of change: a practical guide to developing better day opportunities for people with learning disabilities.* London: Kings Fund.

Marshall, D., McConkey, R. and Moore, G. (2003) Obesity in people with learning disabilities: The impact of nurse-led health screenings and health promotion activities. *Journal of Advanced Nursing*, 41, 147-153

Martin, N., Johnston, G., Stevens, P. (1999) Adults with intellectual disabilities and challenging behaviour in supported employment: Initial findings. *Journal of Applied Research in Intellectual Disabilities,* 12, 149-156.

Mason, J. (1998) Variation in the provision of community day care for people with learning disabilities. *Tizard Learning Disability Review*, 3, 44-45.

Mawhinney, S. (2003) *Learning disability day services in border counties of Ireland: Exploring the potential for cross-Border cooperation.* Belfast: Praxis Care Group.

Mencap (1991) *Empty Days .. Empty Lives: A Mencap report on day services – the vision and the reality.* London: Mencap.

Mencap (2000) *New targets for a new century: Learning disability strategy.* London: Mencap.

Mencap (2003) *Equal Opportunities to Learn? The experiences of people with a learning disability of further education.* Belfast, Mencap.

Mental Health Foundation (1996) *Building Expectations: Opportunities and services for people with a learning disability.* London: Mental Health Foundation.

Messent, P.R., Cooke, C.B. and Long, J. (1998) Daily physical activity in adults with mild and moderate learning disabilities: is there enough? *Disability and Rehabilitation*, 20, 424-427.

Monteith, M and Sneddon, H (1999) *Children and Young People with Disabilities in Northern Ireland Part Two: The Circumstances, Experiences and Aspirations of Young People with Disabilities Making the Transition to Adulthood.* Centre forChild Care Research, Queen's University of Belfast

Neville, M. (1996) Around in a circle. *Community Care,* Feb/March, 4-5.

NIUSE (2003) *A response by people with a learning disabilities to the Employment Support Programme- A consultation on future developments, conducted by NUISE on behalf of the Department for Employment and Learning,* Londonderry, Northern Ireland Union of Supported Employment.

OECD (1986) *Young people with handicaps: The road to adulthood.* Brussels: Centre for Education Research and Innovation (CERI).

Pettifer, C. and Mansell, J. (1993) Engagement in meaningful activity in day centres. *Mental Handicap Research*, 6,

Redmond, B. (1996) *Listening to parents: The aspirations, expectations and anxieties of parents about their teenager with learning disabilities.* Dublin: Family Studies Centre – UCD.

Sands, D.J. and Kozleski, E.B. (1994) Quality of life differences between adults with and without disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 29, 90-101.

Scally,B.G. and McKay, D.N. (1964) The Special Care Service in Northern Ireland: Origins and Structure. *Irish Journal of Medical Science*, June, 267-279.

Scottish Executive (2000) *The Same as you? A review of services for people with learning disabilities*. Edinburgh: Scottish Executive.

Seed, P. (1988) *Day care at the crossroads*. Tunbridge Wells, Costello.

Simons, K. (1998a) *Home, work and inclusion*. York: Joseph Rowntree Foundation.

Simons, K. (1998b) *Living Support Networks: An evaluation of the services provided by Keyring*. . Brighton: Pavilion Publishing.

Simons, K. and Watson, D. (1999a) *New Directions: Day services for people with learning disabilities in the 1990s – a review of research*. University of Exeter: Centre for evidence-based social services.

Simons, K. and Watson, D. (1999b) *The view from Arthur's Seat: Review of services for people with learning disabilities – a literature review of housing and support options beyond Scotland.* Edinburgh: Scottish Executive Central research Unit.

Sines, D. (1999) Identifying the need for respite care for people with learning disabilities in Northern Ireland. *Journal of Learning Disabilities*, 3, 81-91.

Skill NI, (2000) *The views and experiences of disabled students in further education in Northern Ireland*. Belfast: Skill (NI).

Smyth, M. and McConkey, R. (2003) Future aspirations of parents and students with severe learning difficulties on leaving special schooling. *British Journal of Learning Disabilities*, 31,54-59

Social Services Inspectorate (1995). *Opportunities or knocks. Report on the national inspection of recreation and leisure in day services for people with learning disabilities.* London: HMSO.

Sperrin Lakeland HSS Trust (2000) *In whose hands? Learning disabled people – their future*. Omagh: Sperrin Lakeland Trust.

Taylor, B., McGilloway, S. and Donnelly, M. (2001) *Vocational Opportunities in Training for Employment (VOTE) - an evaluation of an initiative for young adults with disability in Northern Ireland*. Belfast: Queen's University.

Towell, D. (1997). *Promoting a better life for people with learning disabilities and their families: A practical agenda for the new government*. London: King's Fund Centre.

Towell, D. (2000) Achieving positive change in people's lives through the national learning disabilities strategy: Lessons from an American Experience. *Tizard Learning Disability Review*, 5, 3, 30 –36.

Ward, L., Heslop, P., Mallett, R. and Simons, K. (2003) Transition: The experiences of young people with learning disabilities and their families in England. *Tizard Learning Disability Review*, 8, 4, 19-28.

Chapter 5:

Children and Young People with a Learning Disability and their Families.

Overview

In many instances a child with severe learning disabilities will be identified at birth or soon after and nearly all are diagnosed by school entry age. The main policy shift has been a complete move away from any form of institutional provision for these children. Nearly all children now grow up in families, either with their natural families or in a small number of instances, with foster or adoptive families.

There are however a very small number of older children and adolescents who need alternative provision away from the family and at present their needs are not well met in Northern Ireland.

The importance of early intervention to promote the child's development is well attested internationally although its implementation is far from universal.

Moreover in recent years the focus has shifted from a focus solely on the child to that of providing supports to the family. However this too has yet to find expression in many of the services currently provided.

A major unresolved issue is the coordination of professional inputs and services to these children and families. Greater involvement of parents in service planning and delivery is also required alongside greater opportunities for young people's views to be heard and acted upon.

This chapter is in three main sections.

Section 1 is recent review of Northern Irish research and policy undertaken by Berni Kelly and Marina Monteith on behalf of the National Children's Bureau and published in 2003. This is reproduced in this report with permission of the Bureau and any quotations from this should acknowledge the authors and publishers.

Section 2 is an Appendum to the Kelly and Monteith review with more details given of additional or pertinent recent research findings in learning disabilities and autistic spectrum disorders within Northern Ireland.

Section 3 is a synopsis of international research that highlights the implication for service developments and practice.

Section 1: Supporting disabled children and their families in Northern Ireland: A research and policy review

Berni Kelly and Marina Monteith

Summary

- The prevailing focus on protective rather than preventive services has limited the development of support services for disabled children and their families.
- Research suggests that parents experience poorly coordinated systems and inadequate services especially at particular stages, such as diagnosis or post-school transitions.
- Respite care services hold potential benefits for disabled children and their families but need to be more flexible, comprehensive, family based and focused on the needs and wishes of disabled children.
- There is a need to develop more integrated recreational, social and leisure opportunities for disabled children to help combat their social exclusion.
- The provision of accessible and inclusive education for disabled children needs to expand alongside initiatives to address bullying on the grounds of disability discrimination in schools and the local community.
- The development of more flexible work patterns and community or school based child care services would be useful for working parents of disabled children.
- Parents should have greater access to professional advice on eligibility for social security benefits or grants for home adaptations, and assistance with application processes.
- Service providers need to more actively involve parents and children in the planning process and listen to their views, especially for children who do not use conventional methods of communication.
- New developments, such as the appointment of a Children's Commissioner and the current review of community and hospital services, should improve support service provision for disabled children and their families in Northern Ireland.

Introduction

Over the past decade there have been major policy reforms regarding service provision for disabled children and their families in Northern Ireland. This legislative progression promised the development of more effective support services for these children and increased recognition of their rights and needs. While there have been some positive service developments, researchers have reported fragmented implementation of these policies and identified outstanding support needs of disabled children and their families in Northern Ireland. These include the need for more flexible short breaks, service coordination, consultation, adequate housing, appropriate postschool transitions and social inclusion. Recent research has provided indications of how support services can be further developed to meet the needs of disabled children and their families. In addition, it is hoped that new developments, such as the appointment of a Children's Commissioner and the current review of community and hospital services, will improve support services for disabled children and their families in Northern Ireland.

Policy and disabled children in Northern Ireland

The Policy Planning and Research Unit (PPRU) surveys of disability in Northern Ireland (1990) remain the main source of detailed statistical information on disabled children in Northern Ireland (PPRU 1992, 1994, 1995; Monteith *et al.* 2002). The absence of a clear and consistent information base on the prevalence and circumstances of disabled children in Northern Ireland inevitably has a detrimental impact on the planning, delivery and evaluation of services provided to meet their needs (Monteith *et al.* 1997; McConkey and McAteer 1999; Monteith *et al.* 2002). Schedule 2 of the Children (NI) Order 1995 requested the establishment of a register of disabled children. The two-year project on the development of this register has just been completed and the first wave of implementation will begin shortly. It is hoped that the future establishment of this register will in some way address this lack of information.

Policies relevant to disabled children in Northern Ireland include the Disabled Persons (NI) Act (1989), the Disability Discrimination Act (1995), the Northern Ireland Act (1998), the Education (NI) Order 1996 and the Children (NI) Order 1995. The Disabled Persons (NI) Act (1989) requires Boards or Trusts to identify the needs of young disabled people leaving school and provide appropriate services. It also established disabled people's right to information, representation, assessment and counselling and recognised the needs of carers to have an assessment of their ability to care. The Disability Discrimination Act (1995) seeks to eradicate discrimination against disabled people and promote equal opportunities. Priority is given to equal opportunities in relation to facets of adult life, such as employment or buying property, rather than issues more relevant for children. Section 75 of the Northern Ireland Act (1998) includes a requirement for public authorities in Northern Ireland to promote equality of opportunity in policy and practice between individuals and groups, including potential inequality related to age and disability and between people with dependants and people without. This legislation requires wide consultation on policy implementation to provide opportunities for individuals and organisations to highlight potential breaches and this should include consultation with disabled children and young people on policies that affect their lives.

The Education (NI) Order 1996 established legal duties for the identification and assessment of children who have special educational needs and issuing of a statement outlining how their educational needs will be met. Parents were granted a legal right to participate in the decision making process about their child's special educational needs and under the associated Code of Practice parents may appeal a decision about the statementing process at the Special Educational Needs Tribunal.

The Children (NI) Order (1995) follows most of the provisions set out in the Children Act (1989) of England and Wales and the Children (Scotland) Act (1995). This legislation recognised disabled children as children first and firmly embraced the inclusion of disabled children within the broad definition of 'children in need' (Article 17). Article 18 and Schedule 2 outlined a range of support services to safeguard and promote the welfare of children in need. There is also an emphasis on multidisciplinary teamwork, working in partnership with families, ascertaining the views and wishes of children, minimising the effect of impairment and providing support services for young disabled people making transitions. Each Health and Social Services Trust also provides policy and procedures handbooks. The 'Children in Need' policies and procedures handbook provides operational indicators of need. However, these operational indicators minimise the original definition in the Order of a child with a disability as a child in need to 'a child with a disability who may require social services care' (SSI 1995). The Children (1995 Order) (Amendment) (Children's Services Planning) Order (NI) 1998 also placed a requirement on Health and Social Services Boards to produce Children's Services Plans every three years in collaboration with other key agencies in Northern Ireland.

Regarding services for disabled children, these plans have highlighted the need for early intervention, advice and support for parents following diagnosis, transitional planning and improved coordination between agencies and professionals. However, it is also recognised that greater levels of funding for social services is required to meet the department's strategic aims in relation to disabled children (Monteith and Cousins 1999; Monteith *et al.* 2002). With regard to international policy, the Human Rights Act (1998) allows individuals to claim their rights under the European Convention on Human Rights (ECHR) in courts in Northern Ireland. The ECHR was ratified in 1951 by the UK. Children's rights were not prioritised, however, it recognises rights related to private and family life, protection, liberty and freedom of speech which are also relevant to disabled children. In addition, Articles 12, 13 and 23 of the United Nations Convention on the Rights of the Child, ratified by the UK in 1991, refer to the participation rights and provision for children, including disabled children specifically. The Convention recommends that policies that facilitate a full expression of the child's view in any decisions made about their lives should be developed.

In particular, Article 23 describes rights for disabled children including their right to care, education and training that promotes self-reliance and active participation in society. Disabled children should also benefit from recent developments in policy for children in general in Northern Ireland. Despite the suspension of the Northern Ireland Assembly, work has continued regarding the development of an all embracing children's strategy for Northern Ireland. This 10-year strategy for children and young people addresses issues such as improving children's services and ensuring children's rights and needs are coordinated, monitored and promoted within government. This is closely linked to the appointment of a Commissioner for Children and Young People in June 2003, who is responsible for safeguarding and promoting the rights and best interests of children and young people. In addition, the Children's Social Services Strategy is currently in the early stages of development with plans for consultation underway for 2003. While having links with the Children's Strategy and the Children's Commissioner, the Children's Social Services Strategy will have the aim of promoting cohesion in the planning and provision of children's services in Northern Ireland. This will also address issues such as those covered by the Quality Protects Initiative in England and Children First in Wales with its emphasis on meeting the stability needs of looked after children. These policy advances for children in general, alongside new legislation addressing the needs of disabled children (SENDA (NI) Bill and Carers and Direct Payments Act (NI) 2002) and the review of community and hospital services for disabled children led by the Social Services Inspectorate, should improve the provision of services for disabled children and young people.

Health and social service provision

The Health and Personal Social Services (NI) Orders (1991) and (1994) placed responsibility for assessment of health and social welfare needs and provision of services on Health and Social Services Boards in Northern Ireland. This established the purchaser/ provider organisation that meant Health and Social Services Boards purchase services for their populations from Health and Social Services Trusts so that services are sensitive to the needs of local communities. However, Monteith *et al.* (1997) noted that, although the PPRU survey estimated there were 14,600 disabled children in Northern Ireland, during the year ending March 1995 only 2,883 disabled children were in contact with a Health and Social Services Trust.

The needs of families with disabled children

Much research has revealed that the pattern of service development in Northern Ireland has prioritised protection and restricted levels of family support services for children (Higgins *et al.* 1998; Geraghty 1999). McCrystal (2000) found that in contrast to the commitment to disabled children in the Children (NI) Order (1995), the key operational indicator of a child in need was a child in need of protection. This narrow interpretation of need ignores the diverse needs of disabled children and their families that should be targeted by service planners and providers (Monteith and Cousins 1999; Kelly 2002a).

Many researchers have discussed the ongoing practical and emotional needs of parents of disabled children (McKeever 2000c; McKeever and Griffiths 2001; Kelly 2002a). However, much of the stress experienced by these parents is directly related to discriminatory barriers and poorly coordinated service systems rather than inevitable effects of caring for a disabled child. For example, the technocratic social security system makes it difficult for parents to successfully complete application processes. In addition, some parents still feel they must argue with professionals and agencies for access to appropriate levels of service provision for their family (McKeever 2000c; McKeever and Griffiths 2001; Family Information Group and Contact a Family 2001; Kelly 2002a). Authors have emphasised the need for support services at diagnostic stages (Mencap 1997; McKeever 2000b; McKeever and Griffiths 2001; Family Information Group and Contact a Family 2001; Kelly 2002a). Such research has found that professionals informed parents about diagnoses in unsympathetic and inappropriate ways, and follow up services were inadequate and uncoordinated. Many parents researched their child's impairment themselves rather than being given adequate levels of information from professionals. Parents not only need information on diagnosis and prognosis but also on the availability of local services, support networks and the roles of different professionals and agencies relevant to disabled children and their families (McConkey 2003). In addition, researchers have found that many families did not receive professional counselling following diagnosis, although parents suggested this would have been of benefit to them (Mencap 1997; McKeever 2000b, 2000c; McKeever and Griffiths 2001). Parents who were not given a diagnosis of their child's disability also experienced problems persuading medical professionals to take their concerns about their child seriously and were often accused of being over-protective parents (Mencap 1997; Kelly 2002a). Researchers have concluded that professionals should receive more training on family dynamics, listening, advocacy, counselling, and conveying positive images of disability while providing accurate information about impairment.

Inter-agency and multi-disciplinary coordination

There is much evidence that, despite legislative intent, there is a lack of inter-professional and inter-agency coordination (Mencap 1997; McConkey and McAteer 1999; McKeever 2000a; Family Information Group and Contact a Family 2001; Kelly 2002a). Monteith *et al.* (2002) found that even within the public sector disabled children often fall between gaps of internal planning and service boundaries. Researchers have indicated that one of the best ways to avoid this is to provide a keyworker for families (DHSS 1996; Mencap 1997; McKeever 2000a, c). Sloper (1999 p91) defined a keyworker as:

> *a named person whom the parent approaches for advice about any problem related to the disabled child. The key worker maintains regular contact as needed with the family, and has responsibility for collaborating with professionals from a range of services, and coordinating support for the family. Particularly important aspects of the service are the key worker's knowledge of and ability to access information and services from a range of agencies.*

However, McConkey and McAteer (1999) found disagreement about which profession should undertake this role. Similarly, Kelly (2002a) found that staff changes and challenges related to interdisciplinary, multi-disciplinary and interagency working can undermine the potential benefits of keyworking.

Respite care services

Researchers have found that the most frequent service provided from social services is respite care, sometimes termed 'short breaks' (Monteith *et al*. 2002; Kelly 2002a). There are potential benefits of respite care for families of disabled children, especially when it is part of an overall package of support services for families rather than the only service (Kelly 2002a). Parents can enjoy opportunities to rest, do household chores or go on family outings. When delivered appropriately respite care can also offer opportunities for disabled children to develop increased independence, have a wider range of social experiences and become more involved in the community.

Generally, the literature suggests that respite care works best for families when it is locally based, provides good quality child care with age appropriate enjoyable activities for disabled children and flexibly responds to needs as required over short periods (McKeever 2000b; Kelly 2002a). However, Mencap (2003) recently conducted a survey of respite care provision involving 76 families, with children or adults who have learning disabilities, from England and Northern Ireland. The study found that six out of ten families were not receiving a short break service or were receiving limited respite care provision that did not meet their needs. Mencap (2003) also discovered that six out of ten families who were on a waiting list for short break services had been waiting for at least six months. This study revealed many carers of children and adults who have severe or profound learning disabilities feel they are driven to breaking point because they cannot access necessary support services.

McConkey *et al*. (2003) argued that increased respite care services and appropriate residential services would help alleviate stress that some families experience. The author emphasised this is particularly relevant for families of adolescents who are dependent on technology or those with autistic spectrum disorders and challenging behaviours.

Research has also demonstrated that parents prefer family-based respite care rather than accommodation in residential or hospital units (McConkey and Adams 2000). However, Prewett (1999) and McConkey and Adams (2000) found that, although they were popular and most cost effective, social and leisure services and family based respite care services were marginalised within social services provision. Prewett (1999) expressed concerns about inadequate preparation and training for family carers, lack of consistency in re-approving carers annually and insufficient monitoring of placements. Kelly (2002a) also discovered that respite care was often provided to meet the needs of parents, rather than children, and disabled children were rarely involved in decisions about the type and frequency of stays at respite care. In addition, Monteith and Cousins (1999) and Kelly (2002a) expressed concern that tools for assessing and reviewing respite care provision provided limited opportunities to include the views of disabled children.

Disabled children and social exclusion

Monteith and Cousins (1999) reported improvements in service provision for disabled children since the enactment of the Children (NI) Order (1995), however, they also revealed limited access to mainstream services for disabled children. This restricted access to common sources of support for parents of disabled children means they must rely on specialist facilities that isolate their child from their peers in the community (McKeever 2000a; McConkey and Adams 2000; Kelly 2002a).

Many studies in Northern Ireland have found that disabled children have restricted social opportunities within local communities, especially for children who have learning disabilities (Monteith and Cousins 1999; Educable 2000; McConkey and Smyth 2000; Kelly 2002a; Monteith *et al*. 2002). Contact a Family's survey of the United Kingdom, including Northern Ireland, highlighted the extent of social exclusion that disabled children experience (73 per cent did not go on outings, 70 per cent cannot attend a youth club and 55 per cent of parents must travel out of their local area to access suitable leisure facilities for their disabled child). McConkey and Smyth (2000) found that young people who took part in leisure activities usually did so in the company of their parents. Monteith *et al.* (2002) also discovered that even when disabled children did have contact with peers in the community they often had negative experiences of bullying. In addition, social contacts at special schools were usually not accessed outside school hours because they lived long distances away and most children did not have opportunities to develop friendships with both nondisabled and disabled children (Kelly 2002a; Monteith *et al.* 2002). Monteith *et al.* (2002) discovered that a lack of established friendships caused young people to become withdrawn and self-reliant. These authors suggested that strategies should be developed to provide safe, accessible play areas and more integrated social activities. However, this would require more adequate ring-fenced funding for services that enable disabled children and young people to access mainstream play and leisure facilities.

Educational services

The first DENI study of provision in mainstream schools in Northern Ireland for pupils with special educational needs revealed serious inadequacies in the implementation of the Education (NI) Order 1986 and a higher rate of 'statementing' of children in Northern Ireland than in other areas of the United Kingdom (DENI 1998). Monteith *et al.* (2002) found that parents felt alienated by the assessment process and insufficiently informed to make a genuine contribution to their child's education. Although legislation promotes inclusive education and the use of mainstream schools for children who have special educational needs, Geraghty (1999) noted that few mainstream schools provide facilities for disabled children. The majority (74 per cent in 1996/7) of disabled children in Northern Ireland in the 1990s were still being educated in special schools or in special units attached to mainstream schools. McConkey and Bhurgri (2003) found that, although mainstream preschool facilities were committed to enrolling children who have autism, staff had inadequate training or lacked knowledge of the skills required to meet the particular needs of these children. Monteith *et al.* (2002) drew attention to particular issues for disabled children in school including difficulty with regard to maintaining friendships and bullying. They recommended that additional funding should target the needs of disabled children in mainstream schools and address physical access problems to facilitate the inclusion of disabled children in mainstream settings. The authors also suggested that initiatives to address racial and sectarian bullying in schools should be extended to include discrimination on the grounds of disability.

The Educable (2000) study, carried out by a group of young disabled people with Save the Children and Disability Action, investigated the educational experiences of over 50 young disabled people in Northern Ireland. They discovered some mainstream schools were inaccessible or did not provide essential specialist services. Children attending segregated schools often felt socially isolated and rarely had social networks outside their own family. Young disabled people felt they were not encouraged to undertake serious study and were restricted by lack of access to computers and other essential aids. In addition, negative teacher attitudes meant that some young disabled people felt they were not treated with respect and not encouraged to develop aspirations for post-school education or employment. Many young disabled people in this study would have liked to have learnt more about living independently and been more actively involved in decisions about post-school training and employment. The study recommended the provision of disability awareness training for teachers, more accessible mainstream schools and transport systems, alternatives to examinations for assessment, increased subject choice, counselling services within schools and the involvement of young disabled people in school councils.

Post-school transitions

Monteith and Sneddon (1999) examined the needs and experiences of 76 young disabled people between the ages of 16 and 21 making transitions to adulthood in Northern Ireland. Although the authors discovered that many young disabled people accessed valued activity for future employment, such as youth training programmes or higher education, the availability of future employment for these young people was limited. In addition, while most young people interviewed did have active social lives, there were concerns for young people who had learning or multiple disabilities who felt more isolated. The authors reported poorly planned and uncoordinated transitional services with limited access to appropriate professionals, especially social work services. In addition, young disabled people were not involved in assessments or reviews and had limited access to information on options or sources of available support. McConkey and Smyth (2000) interviewed young disabled people aged between 18 and 21 and their parents separately about their educational experiences, lifestyles and aspirations for the future. The majority of young disabled people were dependent on their parents for personal care which restricted opportunities for them to become self-reliant. Parents had limited access to social work services and at transitional stages required information about social security benefits and services, respite care breaks, leisure activities for young disabled people and practical assistance in the home. An interesting finding in this study was the difference between the views of young disabled people and their parents. Although almost all of the young people wanted to access employment, only half of their parents agreed this was possible. Parental views contrasted even more with their child on the subject of sexuality and marriage. The authors emphasised the importance of parents, professionals and young disabled people working together on a risk-taking strategy to promote self-reliance.

Employment and social security

Monteith *et al*. (2002) noted that childhood disability was strongly associated with reduced income levels. Several researchers have noted how mothers often give up paid employment to care for their disabled child and fathers are also restricted in their choice of employment and opportunity for promotion (Kelly 2002a; Monteith *et al*. 2002). Reduced income has a detrimental impact on the ability of families to cover extra costs related to caring for their disabled child such as home adaptations, specialised diets or equipment. Difficulty in accessing local child care provision for families of disabled children is of particular concern and demonstrates the need for implementation of the duties and powers within the Children (NI) Order 1995 to integrate disabled children into mainstream child care provision (Kelly 2002a). The development of more flexible work patterns, community or school based child care services and adequate access to support systems for working parents would also be useful for families of disabled children (Monteith *et al*. 2002). Given the fact that some parents of disabled children experience difficulties related to employment, findings by Monteith *et al*. (2002) that a third of families rely totally on social security benefits for income is hardly surprising. In addition, the authors found that lone parents of disabled children were more than twice as likely to be dependent on social security benefits than twoparent families. Despite the importance of state benefits for these families, researchers have found that complex benefit systems often result in inadequate financial support for parents. It was estimated in 2001 that nearly 300,000 families in the United Kingdom were not receiving the benefits they should have been (Contact a Family 2002). Mencap's (1997) report recommended that parents should have access to professional advice on eligibility and the application process. Since benefits are entitlements, and can improve quality of life and wellbeing, they should be easily accessible (McKeever 2000c; Monteith *et al*. 2002).

Housing services

McKeever (2000c) acknowledged that the housing needs of children with disabilities and their families can be complex and change as children grow older. Appropriate housing for disabled children is crucial to ensure their basic needs, such as safety and space, are met. However, McKeever (2000c) and Monteith *et al*. (2002) commented on the difficulty of obtaining grants for home adaptations and the high levels of bureaucracy involved.

Based on the PPRU data, Monteith *et al.* (2002) found that in 1990 families of disabled children in Northern Ireland were less likely to afford their own home. In addition, these authors noted that there is no public finance available for families who need to move to a new home with more adequate space for their disabled child and recommended increased disability awareness among those designing new homes. Hopefully, implementation of the Housing Support Services Bill should recognise more fully these housing needs of disabled children and their families.

Listening to disabled children and young people

Much research has identified the need for policy makers and service providers to work in partnership with children and parents and harness their expertise to develop effective services for families (Higgins *et al.* 1998; Pinkerton 2000; McKeever 2000b). The fundamental right of disabled children to be listened to and understood is reflected in current policy, such as the Children (NI) Order 1995, and the United Nations Convention on the Rights of the Child. Yet there has been little effort to include these children in crucial decisions that affect their lives or the services provided to meet their needs. This is particularly the case for children who have learning disabilities and those who do not use verbal communication (Kelly 2002a). Monteith and Cousins (1999), Monteith and Sneddon (1999) and Monteith *et al.* (2002) found that professionals were aware of the need to consult disabled children and young people but highlighted difficulties such as dealing with conflicting views of parents and children. Likewise, Kelly (2002a) discovered that social workers felt they did not possess the necessary skills or experience to communicate effectively with disabled children. Policy makers and service providers need to actively involve parents and children in the planning process and listen to their views so that public services can develop to more effectively meet their needs. The absence of consultations with disabled children and young people means that service providers are reliant on adult interpretations of their needs. Aside from the denial of the child's right to contribute their views and be involved in decisions affecting their lives, this is also inappropriate since studies have shown that the views of parents and children are often very different and parents are not always their child's best advocate (McConkey and Smyth 2000; Monteith and Sneddon 1999). Hence, it is important that service providers consider how to ask questions, what methods of communication should be employed and how much time is available to consult disabled children in an ethical and appropriate manner without the presence of other adults. Several researchers have employed creative methods that practitioners could use to involve disabled children and young people in decision-making (Educable 2000; Monteith 2002; Kelly 2002a; Kernohan 2003). Indeed, Kelly (2000b) discussed methods one Health and Social Services Board used to involve young disabled people in a steering and reference group for Children's Services Planning. Monteith *et al.* (2002) and Kelly (2002a) explored the views of disabled children and parents and found that parents and professionals often did not appreciate the extent of their children's awareness of feeling different from others. Most families rarely discussed disability with their disabled child and children's awareness of disability was often founded on negative experiences such as sibling rivalry or bullying. These authors suggested that parents should have access to information and support on how to guide their child through the experience of growing up with a disability, especially how to overcome disabling barriers they are likely to encounter.

Conclusion

Research has provided valuable information on how support services in Northern Ireland can be targeted to meet the needs of disabled children and their families, some of which is based on the views of these children and their parents who are most able to identify the types of services they require. It is imperative that this knowledge is incorporated into the delivery and development of support services in Northern Ireland. Likewise, future research initiatives should further develop understanding of the lives of disabled children and young people in Northern Ireland and seek to address gaps in current knowledge such as disabled children's identity, personal and sexual relationships and educational provision for young people who have learning disabilities.

Two crucial gaps in service provision for disabled children and young people emerging from the literature are access to social networks and opportunities to have a say in decisions about their lives and the support services provided to meet their needs. Indeed, Monteith *et al.* (2002) recommended that the Equality Commission and the Assembly in Northern Ireland should urgently lead holistic disability awareness and equality programmes targeted at all staff in the public sector. New developments in Northern Ireland, such as the current review of services for disabled children and the introduction of the Carers and Direct Payments Act (NI), should advance service provision for disabled children and their families. If the necessary resources are forthcoming, these developments should impact positively on services for disabled children and their families in Northern Ireland.

References

Contact a Family (2002) *Everybody Here?* Contact a Family

Department of Education (NI) Research Report II (1998) *Practice in Mainstream Schools for Children with Special Educational Needs.* DENI

Department of Health and Social Services (1996) *Review of Policy for People with Learning Disabilities.* HMSO 2/95, Dd 8400949, C10, 14575

Educable (2000) *No Choice: No Chance. The Education Experiences of Young People with Disabilities.* Save the Children

Family Information Group and Contact a Family (2001) *Parents Stories.* Guildhall Press

Geraghty, T (1999) *Getting it Right? The State of Children's Rights in Northern Ireland at the End of the Twentieth Century.* Children's Law Centre

Higgins, K, Pinkerton, J and Devine, P (1998) *Family Support in Northern Ireland. Part II Perspectives from Practice: An Overview of the Five Process Evaluation Reports.* Centre for Child Care Research, Queen's University Belfast

Kelly, B (2002a) *The Provision of Family Support Services for Children who have Learning Disabilities and their Families in the Context of Current Social Policy and Legislation.* Unpublished Thesis, University of Ulster at Magee

Kelly, B (2002b) Disabled Children as Active Citizens, *Child Care in Practice*, 8, 3, 220–222

Kelly, B, McColgan, M and Scally, M (2000) A Chance to Say: Involving Children who have Learning Disabilities in a Pilot Study on Family Support Services, *Journal of Learning Disabilities*, 4, 2, 115–127

Kernohan, G (2003) *Methods of Involving Disabled Children and Young People in Children's Services Planning.* Southern Area Children's Services Planning and University of Ulster

McConkey, R and Adams, L (2000) Matching Short Break Services for Children with Learning Disabilities to Family Needs and Preferences *Child: Care, Health and Development*, 26, 5, 429–443

McConkey, R (2003 forthcoming) Information Needs of Parents about Learning Disabilities, *Journal of Learning Disabilities*

McConkey, R and Bhurgri, S (2003 forthcoming) Children with Autism Attending Preschool Facilities: The Experiences and Perceptions of Staff, *Journal of Early Childhood Education*

McConkey, R and McAteer, D (1999) The Contacts which Families and Children with Learning Disabilities have with Health and Social Services *Child Care in Practice*, 5, 2, 112–121

McConkey, R and Smyth, M (2000) *Not So Different? The Experiences and Views of Parents and School-Leavers with Severe Learning Difficulties* University of Ulster and Eastern Health and Social Services Board

McConkey, R *et al.* (2003 forthcoming) The Characteristics of Children with a Disability Looked After Away from Home and their Future Service Needs, *British Journal of Social Work*

McCrystal, P (2000) *Children in Need: Implementing Article 18 of the hildren (NI) Order 1995 The First Two Years*, Centre for Child Care Research, Queen's University Belfast

McKeever, B (2000a) *Bridging the Gap?Professionals Together: Parents, Voluntary and Statutory Workers in Partnership – Can it Work?* Family Information Group

McKeever, B (2000b) *More Than Just Time Out.* Guildhall Press

McKeever, B (2000c) *Listening to Parents: Parents as Professionals.* Guildhall Press

McKeever, B and Griffiths, H (2001) *In the Telling: Research into the Experiences of Parents, Recalling How their Children were Diagnosed with Disabling Conditions.* Guildhall Press

Mencap (2003) *Breaking Point. A report on caring without a break for children and adults with severe or profound learning disabilities.* MENCAP

Monteith, M and Cousins, W (1999) *Children and Young People with Disabilities in Northern Ireland Part Three: Social Services Developments and the Impact of the Children (NI) Order 1995.* Centre for Child Care Research, Queen's University of Belfast

Monteith, M, McCrystal, P and Iwaniec, D (1997) *Children and Young People with Disablities in Northern Ireland Part One: An Overview of Needs and Services.* Centre for Child Care Research, Queen's University of Belfast

Monteith, M and Sneddon, H (1999) *Children and Young People with Disabilities in Northern Ireland Part Two: The Circumstances, Experiences and Aspirations of Young People with Disabilities Making the Transition to Adulthood.* Centre for Child Care Research, Queen's University of Belfast

Monteith, M. *et al.* (2002) *Is Anyone Listening? Childhood Disability and Public Services in Northern Ireland.* Barnardo's

Policy Planning and Research Unit Statistics and Social Division (1992) *The Prevalence of Disability Among Children in Northern Ireland.* Policy Planning and Research Unit

Policy Planning and Research Unit (1994) *Disabled Children in Northern Ireland: Services, Transport and Education.* PPRU

Policy Planning and Research Unit (1995) *Northern Ireland Annual Abstract of Statistics.* PPRU

Prewett, B (1999) *Short-Term Break Long-Term Benefit: Family-Based Short-Term Care for Disabled*

Children and Adults. Joint Unit for Social Services Research

Sloper, P (1999) Models of Service Support for Parents of Disabled Children: What Do We Know? What Do We Need To Know? *Child: Care, Health and Development*, 25, 2, 85–99

Social Services Inspectorate (1995) *The Challenge of Partnership in Child Protection: Practice Guide*. HMSO.

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The Foundation has recently completed an 8 year programme of research and development work on disabled children and young people, mostly based in England. Summaries of the main policy

and practice messages and research findings from this work are available free of charge from the Joseph Rowntree Foundation: Louise Ross, Research Department, JRF, 40 Water End, YORK YO30 6WP (Tel: 01904 615942; Email: Louise.Ross@jrf.org.uk) or downloaded from the JRF website: www.jrf.org.uk

Other relevant research summaries include: "*Supporting disabled children and their families*" (JRF Foundations November 1999 Ref N79) and "*Moving into adulthood: Young disabled people moving into adulthood*" (JRF Foundations June 2002 Ref 512).

Section 2: Children and families with a learning disability in Northern Ireland

This section of the reports expands on certain themes from Section 1 with particular reference to children and families with learning disabilities.

Numbers of children and families

Children with a learning disability in Northern Ireland are recorded on the Child Health System – Module V. In addition, if the child and family receive social services from a HSS Trust, they should be recorded on Soscare. A study had been undertaken of the administrative prevalence of learning disability based on data from these two systems in 2002 (McConkey, Spollen and Jamison, 2003).

A total of 8,231 children and young people who had a learning disability and who were aged 19 years and under were recorded. This gives an overall prevalence rate of 16.42 per 1,000 of the child population. Of these 79% were recorded as having a moderate learning disability and 21% as severe/profound disability. This is a considerably higher than the rate noted in the Irish Republic (Health Research Board, 2003) which in 2001 had 7.75 per 1,000 recorded on their intellectual disability database. It is likely that the Northern Irish system records children whom community pediatricians consider *may have* a learning disability whereas in the Irish Republic the systems records children with a confirmed diagnosis in receipt of services.

However in both countries the rates vary according to the age bands as Table 1 shows

Table 1: The number of children with a learning disability by age bands

Age Bands	NI Number	Rate per 1,000	RoI Number	Rate per 1,000
0-4 years	364	3.17	1021	4.08
5-9 years	1721	14.03	1955	6.91
10-14 years	2968	22.21	2885	8.85
15-19 years	3178	24.42	3361	9.90
Total	**8231**	**16.42**	**9222**	**7.75**

This data suggests that in Northern Ireland considerable numbers of children are not identified until school age.

Moreover in Northern Ireland around 30% of the children were also included in the Soscare systems which gives an indication – albeit possibly an incomplete one – of those in receipt of social services. (However this varied significantly across HSS Board with 49% of children recorded in the WHSSB and 15% in NHSSB.). This would give a rate of 4.88 per 1,000 which is much lower than the rate in contact with services in the Irish Republic.

However the Irish data also includes school attendance. In Northern Ireland, 7,222 children had statements of special educational needs for the period 1997 to 2002 (O'Connor, Hartrop and McConkey, 2003). Of these, around 60% are for learning difficulties. This suggests that some 4,300 children had a 'diagnosis' of moderate or severe learning disabilities: a rate of 8.6 per 1,000. It is possible that most of these children are included in the Soscare records. This suggests that Northern Ireland may have a higher proportion of children with a learning disability than the Irish Republic. Moreover the figures are probably higher than in Great Britain although comparable data is not available nationally. However these comparisons are fraught with difficulties if common assessment criteria are not employed.

Looked after children

Data is not available for all of Northern Ireland on the numbers of children with a learning disability who are looked after away from their natural families. A survey in the largest HSS Board, found that 53 children were living in some form of residential accommodation (N=31) or with foster carers (N=22) (McConkey et al, 2004). This represents 0.28 per 1,000 child population or 3.3% of children with recorded learning disability in the Board area (using the corrected figure of 8.6 per 1,000 – see above). If these figures were projected to Northern Ireland as a whole, this suggests that around 140 children live away from their natural families. Most of the children in residential accommodation were 14 years and over.

In the Republic of Ireland, twice as many children (7%) live in some form of residential accommodation with an unknown number in foster care arrangements (Health Research Board, 2003).

However the Northern Irish study suggested that in the Eastern HSS Board area an additional 16 places were required to met the needs of those young people presently living with families but a further 14 places are also needed for those inappropriately residing in hospital or adult residential accommodation. (If an extra 16 places were to become available, the proportion of places would still be significantly lower at 4.3% than for the Irish Republic.)

If the figures for increased needs were projected to Northern Ireland as a whole, an additional 75 places are required for young people who need to live away from the family home. Many of these young people have severely challenging behaviours and autistic spectrum disorders. They are difficult to foster because of their complex behavioural problems or health needs and they can be difficult to accommodate in mainstream children's homes.

However, increasing residential places for young people necessitates planning for their adult years in order to ensure continuity of their care and this needs to be factored into projections of future accommodation and support needs (see Chapter 3).

Database of unmet needs

Planning for service improvements is hampered by a lack of data about the needs of families. None of the existing databases in use in Northern Ireland are set up to provide information about family circumstances or their needs for services. The proposed Register of children with disabilities to be set up under the Children (NI) Order is also unlikely to do this. This means that the evidence required to argue for increased funding is not readily to hand.

The Intellectual Disability Database in the Irish Republic does record unmet needs although the published data does not give information broken down by age. The most common need was for more respite breaks.

Short breaks – out of the family home

The demand for increased respite breaks has also been documented in Northern Ireland (Sines, 1999). Families preferred the option of after-school or leisure activities at evenings and weekends or having a 'flexicare worker' come to the family home (McConkey and Adams, 2000). More homely services, serving small numbers of compatible children, were preferable to other forms of residential provision. The features that parents identified as distinguishing 'better services' are noted in the box (McConkey, Truesdale and Conliffe, 2004).

Box : Features of preferred short break service

- Small numbers of children at a time
- Homely environment
- Located in pleasant surroundings
- Low risk of abuse
- Child looks forward to going
- Child orientated service
- High standard of care provided
- Children are shown love and affection
- Stimulation and activities for the children
- Gives me someone to talk to
- I meet other parents
- I'm told about other services

Accessing play and leisure activities

Children and teenagers with disabilities are often unable to access mainstream play and leisure activities. A study in the Greater Belfast area involved a postal survey of over 130 summer schemes and play and leisure facilities (Thompson, Taylor and McConkey, 2000). Around one-third of schemes had experience of taking a child with some form of disabling condition. However the biggest obstacles to the inclusion of these children were the lack of training for leaders, insufficient staff and resources.

A linked study involved the evaluation of a model service aimed at supporting five mainstream summer schemes which enrol children with severe learning disabilities and complex needs, such as autism and multiple disabilities. This showed that such schemes are feasible with most children attending regularly and taking part in a range of activities. Family reactions were also positive as were those of the volunteer helpers and other people involved in the schemes. Few problems were reported but many benefits were cited especially for the other children attending the scheme. The study confirmed the importance of training, the use of dedicated volunteer helpers and the need for a co-ordinator to liase with families and to support and advise summer scheme and centre staff.

A survey of 56 staff working in 38 preschools of various types in the Greater Belfast area found that a sizeable number had the experience of taking children with autistic spectrum disorders and staff receive some advice and support from a range of professionals (McConkey and Burghri, 2003). Nearly all were committed to enrolling such children in the future but they felt that a lack of staffing could preclude this. A majority of staff felt they have had inadequate or no training to equip them to meet the children's particular needs and they report a lack of knowledge and skills to help these children.

Subsequently a 10-hour training course on autism was devised and evaluated with a self-selected group of 62 preschool personnel from a range of facilities (Crawford et al, 2004). It aimed to enhance participant's knowledge about autism and of the intervention strategies that are effective in assisting young children with this condition to communicate and interact with others as well as structuring their learning through play and more formal tasks.

The course was well received by the participants who three months later had implemented much of the advice given on the course. Course participants appeared more willing to enrol children with autistic spectrum disorders in their groups although a minority did express some reservations. A resource pack for tutors has been prepared so that similar courses can be delivered elsewhere in the future.

In summary, there appears to be a willingness among community personnel to include children with a learning disability in mainstream play and leisure schemes. Training inputs are welcome and appear successful in boosting the confidence and competence of staff.

Information needs of parents

A common complaint from parents is the lack of information available to them. A survey of over 400 parents and carers of children and adults with severe learning disabilities in N. Ireland found that the most commonly mentioned informants were social workers and staff in schools and centres (McConkey, 2003). In addition, GPs were named by nearly one-third respondents but little use had been made of voluntary services such as Mencap and Citizen Advice Bureau. A similar pattern was found regarding the informants they would approach in the future.

The most commonly reported topics on which parents would seek information were the availability of services, leisure and holidays and benefits. However other topics varied according to the age of the child, with parents of children under 10 more likely to want information on education and therapies.

The preferred means of getting information was through face-to-face contacts in the home and this was particularly marked with parents or carers of adult persons. It was concluded that any specialised information service must be promoted among professional staff and should work in close partnership with them if the information needs and preferences of parents are to be effectively addressed.

Maternal stress and well-being

The presence of a disabled child is known to increase family stress and parental ill-health (see Section 3). However it unclear the extent to which support services can alleviate this.

Families using two, short-break services – both residential and domiciliary - formed the study population (N=68) (Truesdale and McConkey, 2001). Significant proportions of these mothers were stressed and had high levels of psychiatric morbidity. The sole predictor of stress was parental ill-health which in turn was linked with children who had higher scores on motor skills and the presence of other disabled dependents in the family. Families who were most stressed or in poorer health received no greater amounts of support.

A wider ranging study nearing completion by Truesdale (2004) involving over 100 mothers and fathers from over 70 families, has again confirmed that support from professionals has little impact on the levels of stress and well-being of mothers or the coping strategies employed by families. In the main professional support is more closely linked to the characteristics of the child rather than on the needs of families. However there was some evidence that a new style of service, based around person-centred approaches and creating opportunities for young people to be involved in community-based leisure activities, did result in improved scores on a measure of family functioning. The main reasons appear to be that families have more time for themselves and for their other children.

These findings reinforced the complexity of disentangling the relationships between family needs and service supports. The findings also suggest that existing presumptions about more services reducing family stress are too simplistic. The meaning of support for families needs to be critically reviewed along with an examination of the coping strategies used by families. This should result in better matching of support services to individual family needs.

Standards and Outcomes

The emphasis on evidence-based practice and the need to evaluate service outcomes against 'best value' criteria have yet to felt in family services. Supporting families – mothers in particular - rarely features explicitly in the job description of many members of the multi-disciplinary team. It is to be hoped that the Inspection of Children's services will identify the importance of defining the standards that will form the hallmark of quality family support services (see Section 3). The recently produced 'Manifesto' for Wraparound Projects in the SHSSB area (2003) is a further example of explicit service standards.

References

Crawford, H., Doherty, K. Crozier, B., Bhurgri, S. and McConkey, R. (2004) An evaluation of a short training course on autism for preschool personnel. *Good Autism Practice Journal (in press)*

Health Research Board (2003) *National Intellectual Disability Database: Annual report 2001.* Dublin, Health Research Board.

McConkey, R. (2003) Information needs of parents about learning disabilities. *Journal of Learning Disabilities*, 7, 211-219.

McConkey, R. and Bhurgri, S. (2003) Children with autism attending preschool facilities: The experiences and perceptions of staff. *Early Child Development and Care*, 173, 443-452

McConkey, R., Nixon, T. Donaghy, E. and Mulhearn, D. (2003) The Characteristics of Children with a Disability Looked After Away from Home and their Future Service Needs. *British Journal of Social Work (in press)* .

McConkey, R., Spollen, M. and Jamison, J. (2003) *Administrative prevalence of learning disability in Northern Ireland.* Belfast: DHSS&PS

McConkey, R., Truesdale, M. and Conliffe, C. (2004) The features of short-break residential services valued by families who have children with multiple disabilities. *Journal of Social Work (in press)*

O'Connor, U., Hartrop, B. and McConkey, R. (2003) Parental attitudes to the statutory assessment and statementing on special educational needs. Belfast, DENI.

SHSSB (2003) An interim evaluation of the Wraparound Project. Armagh: SHSSB.

Sines, D. (1999) Identifying the need for respite care for people with learning disabilities in Northern Ireland. *Journal of Learning Disabilities*, 3, 81-91.

Truesdale, M. (2004) An investigation of the impact of support services on families caring for a child with a learning disability. PhD Thesis, University of Ulster.

Truesdale. M. and McConkey (2001) Maternal health and stress in families with a child who has multiple disabilities. *Child Care in Practice*, 7, 143-152

Thompson, B., Taylor, H. & McConkey, R. (2000) Promoting inclusive play and leisure opportunities for children with disabilities. *Child Care in Practice*. 6, 108-123

Section 3: International literature

An extensive literature exists on children and families, although mostly from American and British researchers. For the purposes of this paper, the focus is on four main themes:

- What's different about families who have a child with disabilities?
- What problems do parents encounter with services?
- What supports are effective for families?
- Priority Issues in Service Development

At the outset though, the common shortcomings in this research have to be acknowledged.

☐ Little regard has been paid to the possible cultural and societal differences among families who have a child with a learning disability. There has been relatively little cross-cultural research; hence findings from one culture may not apply to others. There are indications for example, that Northern Irish families different in some respects from those in other parts of these islands although few formal comparative studies have been undertaken.

☐ Much of the research has been cross-sectional with few longitudinal studies hence we have an incomplete picture as to the ongoing impact on families of having a child with a learning disability.

☐ In recent years there have been major changes in family life within these islands with more single parenting; fewer children in families; more working mothers and a lessening dependence on the extended family. The ramifications of these changes have yet to be fully explored in the literature but their impact may already be felt within services.

☐ The focus of much research has been on mothers with comparatively little research on fathers and siblings, and still less on documenting the experiences and feelings of the child with disabilities.

☐ The thrust of much research has been on describing the common experiences and impacts on families and on discovering why certain families cope better than others. But given the great variation in terms of the children's characteristics, parents' background and attitudes, family compositions and local societal influences, these common influences may be of little practical significance with service responses needing to be designed for each individual family.

In sum, although a great deal has been learnt about the impact on families of having a child with disabilities, much remains to be discovered.

Finally there is a small but growing body of research into the needs of parents who themselves have learning disabilities although their offspring may or may not be similarly affected. This issue is not considered specifically in this review except to state that much of the insights into best practice equally to this client group and it is the augmentation of these supports that offers the best hope of sustaining these families and ensuring the well-being of all its members (Department of Health, 2001a).

What's different about these families?

A great deal of research has been carried out contrasting families who have children with various disabilities and those who have non-disabled children. There are conflicting results often due to differences in the samples and measures used. Even so, a number of consistent findings have been reported. However the impact on mothers has been studied more thoroughly than the impact on fathers.

Latterly the conceptual models underpinning this research have expanded beyond examination of 'atypical' individuals towards an investigation of the social and environmental factors that impact of the lives of families. The inter-relationships among all these variables should be noted. The presence of a child with disabilities may not be the main cause of the family's distress or of the need for service supports.

- Mothers – and to a lesser extent fathers – report higher levels of stress. It appears that it may be the child's behaviour or sleeping problems, rather than type or severity of disability, that is associated with greater stress (Stores, 1992).
- Mothers are more likely to report symptoms of ill-health; particularly depression (Andersson, 1993).
- Families of disabled children have lower incomes than other families and are more likely to experience social deprivation. They face extra costs that are not always covered by disability benefits (Glendinning, 1992).
- Mothers are less likely to be in employment – either part-time or full-time (Booth & Kelly, 1999). Single parents then face extra challenges (Beckman, 1983).
- Families may receive less informal support from family and friends especially if the child has more complex care needs. They have fewer opportunities for leisure pursuits and breaks (Twigg & Atkin, 1994).
- Families experience more problems with poor housing and lack of transport (Twigg & Atkin, 1994).
- Families may have other dependents to care for, including a second child with a disability; an ageing carer or a sick or disabled spouse (Department of Health, 2001b).
- The care of a child with a disability often extends into adulthood. Many continue to live with their parents until middle age and when the parents are no longer are able or available to provide a home (Harrison, 2000).

Families who face particular challenges - and those more likely to find that their needs are not met - include families with:

- Children who have very severe impairments (including those who are technologically dependent) who require high levels of nursing and personal care (Redmond and Richardson, 2003).
- children and adults with challenging behaviours and mental health problems (Maes et al, 2003)
- More than one disabled child.
- Families from ethnic communities (Hatton et al, 2003).

What problems do parents encounter with services?

Over the past 20 years there appears to have been little improvement in meeting the substantial unmet needs in parents with disabled children. Why should this be?

- ☐ The focus of professional attention is on the child with disabilities. No one professional has the responsibility to ensure that the needs of carers are met. Indeed parents often ignore their own needs and those of other family members as they 'battle' for the help they feel that will benefit their child.
- ☐ Disabled children and their families require interventions from many different services, such as education, hospitals, primary healthcare, therapists, social services, housing and benefits agencies. They have numerous contacts with different workers (McConkey and McAteer, 1999). Although these bring benefits, the problem is often the lack of co-ordination of the work of these different agencies which may result in confusion and conflicting advice and demands on parents (Sloper, 1999).
- ☐ Although an assessment of carer needs is now enshrined in legislation in the United Kingdom; fewer than 50% are thought to have had an assessment made and of those assessed as requiring respite breaks, over a third will not have had this service (Carers National Association, 2000; Williams and Robinson, 2000).
- ☐ A common complaint from families is the lack of information available to them in accessible formats about the services available to them and their entitlements to services .. about the roles of different agencies and workers ... and to know who to go to for help.
- ☐ Services are not equally available across all geographical areas. A so-called 'post-code lottery ' exists.
- ☐ Children and teenagers with disabilities experience high levels of social exclusion in leisure activities and friendships with non-disabled and disabled peers. This places a greater onus on parents and can lead to a greater dependency among the young people and fewer opportunities for controlled risk-taking.
- ☐ Transitions seem to pose particular difficulties for parents' notably from school to adult services; from 'children's teams' to 'adult teams'. Familiar personnel and routines are replaced by uncertainty and people who are new to the family (Ward et al, 2003).
- ☐ Changes in society has placed new demands on parents; for example the breakdown of extended families and people moving to new neighbourhoods. Also the expectations of parents are higher. They expect services as a right not as an act of charity.
- ☐ The relationship between parents and professionals is often combative. For example: "*In many services a culture has developed that sees families as a problem and difficult to work with ... services need to find constructive and positive ways to work with families in the best interests of people with learning disabilities. (DHSS, 2001b)* Many professionals receive little or no training in working with families.
- ☐ Professionals can inadvertently over-emphasise the negative effects of having a child with disabilities. They overlook the positive impact that the child can have on family life (Hasting et al, 2002). These attitudes spill over to the wider community

with consequent hurt to the parents and the young people with disabilities as they encounter stereotypical reactions of pity and rejection (Dale, 1996).

☐ The changing nature of families – single parenting; remarriages; working mothers – is not always reflected in the expectations professionals hold about parents primarily as carers of the disabled child and failing to appreciate the many other roles they play (Carpenter, 2000). Moreover meeting times that suit professionals are not always convenient to parents.

What supports are effective for families?

Although the needs of parents are well documented, there is less empirical evidence as to the professional supports and systems that demonstrably make a difference.

Indeed it has been found that more engagement with professional services can increase the stress and demands on parents to the inadequacy of provision, protracted negotiations and disagreements with service providers (Smith et al., 2001). Others have noted that it is the satisfaction with each source of support that is a better predictor of the quality of a support networks quality rather than the number of sources (Dunst, Trivette & Cross, 1986). Another emphasis has been on the need to build trusted relationships between the parents and the 'supporters' rather than the type of service provided (Cotterill, Hayes, Flynn and Sloper, 1997).

Moreover families will differ greatly in their needs for services and preferences as to the form they take. This means that there is unlikely to be a main effect across all parents but rather the focus should be on understanding which services benefit which parents at which points in time. This research has barely begun to happen, particularly as there has been a scarcity of longitudinal studies.

However, experience of service personnel and the outcomes of service evaluations has started to identify some of the supports that appear to help most families, most of the time.

Key-worker or link person

S/he maintains regular contact as needed with the family, and has responsibility for collaborating with professionals from a range of services, and of co-ordinating support for the family (see Section 1 of this chapter). Particularly important are the key-workers' knowledge and ability to access information and services from a range of agencies. This extends across social services, health, education and community services (both formal and informal). Research suggests that fewer than one third of families in Great Britain have a named worker they can call on (Sloper, 1999). However there is no legal requirement on UK services to provide a named worker unlike other countries (e.g USA).

Partnership styles of working

Effective support for families is largely based around interpersonal aspects of the relationship between families and service personnel. Features of effective help-giving have been identified as relationship building; clear and open communication, honesty and clarity, understanding of families' own concerns and responsiveness to family values and goals. Mothers often rate the helpfulness of professionals on these criteria rather than their technical competence. Parents also appreciate the regular, long-term contact they have with professional workers (Barr, 1999).

Individual Family Plans

In the United States, a legal requirement of early intervention programs with families of disabled children is for a written family plan to be drawn up that integrates the diverse inputs that families will receive as well as documenting the 'informal' contribution of parents, siblings and the extended family to the child's growth and development. Such plans encourage inter-professional sharing and joint working in assessing and planning for the family as a whole.

Breaks from caring

Many carers testify to the value of having planned breaks from caring. These have mainly taken the form of the child being cared for in a residential setting away from the family home. However to date there is little empirical evidence that such breaks have consistent or enduring beneficial effect on carers' well-being (McNally et al, 1999). A possible explanation is the failure of such schemes to forge supportive relationships with the carers. Families in N. Ireland have reported a preference for more leisure activities in the form of evening and weekend activities that would provide their child with positive experiences while also giving the parents a break from caring (McConkey and Adams, 2000.)

Parent Counselling

Various studies have demonstrated the value of offering group or individual based counselling to parents/families who have children with disabilities (Singhi et al., 1990). This can be done informally through parent self-help groups or parent associations, or as a planned series of meetings facilitated by trained counsellors. This approach has been used most often with parents whose child has been newly diagnosed. However not all families wish to meet other parents.

Parent Training

Reports on interventions that focus on training parents to acquire or develop certain coping skills are more common in the USA than in UK (Baker, 1988). The training may focus on particular child problems such as behaviour management or sleep difficulties, or else the emphasis is on more general parenting skills such as training in problem-solving and decision-making, communication, and accessing and utilizing social networks.

Informal supports

The impact of informal supports (e.g. from family, friends and neighbours) has been found to have greater impact on families than professional supports. Some commentators promote the need for professionals to mobilise locally-based informal supports for families, e.g. through parent-to-parent schemes; enrolment in Mother and Toddler Groups and playgroups. Also the important role that these supporters play in the lives of the families should be recognised by inviting them to be present at key events, e.g. appointments, training courses (Carpenter, 2000).

Practical Assistance

Housing adaptations, the provision of suitable aids and equipment, and assistance with transport are all practical ways of reducing strain and stress in families. Yet many families describe having to 'battle' for these and other supports; the bureaucratic and complex procedures involved, as well as the prolonged waiting times before they are made available (Bevan, 2002).

Summary

The Box summarises the features of a quality family support service. These can form the basis of standards that have been proposed for evaluating family support services.

Features of a Quality Family Support Service

(Adapted from Sloper 1999)

- The service takes a holistic approach to assessing and meeting the family needs;
- The importance of relationship building between parents and professionals is recognised. Home visits feature as part of their work and first names are used.
- They provide a consistent, single point of contact for the family, such as a link or key-worker. They should be contactable at evenings and weekends to facilitate working mothers.
- They have a flexible, individualised, needs-led approach to their work with families and children. A menu of services needs to be provided rather than prescriptive programmes.
- The parents' own expertise with regard to their child and family is recognised, and actively sought when professionals undertake assessments of the child and when service plans are drawn up.
- They focus on parents' own concerns and recognise the importance of understanding parents' own perceptions of their priority needs;
- The support provided to parents empowers them rather than taking control away from them.
- Siblings and other close relatives such as grandparents are included.

Priority Issues in Service Development

Various commentators have identified a number of common issues that services need to address. Their importance will vary from area-to-area and across services. Hence an audit in each locality (e.g. local government of Trust area) would identify particular shortfalls. This would also help to reduce inequalities in service availability.

Moreover families of children with severe learning disabilities/difficulties tend to be better served than those whose children have physical or sensorial disabilities and chronic illnesses.

Information

A report for DHSS expressed it thus: *"A requirement on authorities to offer, and to publicise a range of services to people with (learning) disabilities that need to be on offer if people are to have a real choice in the sort of provision they have access to.*

(This models requirements under section 17 of the Children Act)". Research in N. Ireland has confirmed this need (McKeown et al, 2001).

Parental Advocacy

Arguably some, perhaps many parents of children with disabilities have been reluctant to advocate for their needs. Although this is changing – notably in education and the choice of schooling - but even here parents benefit from the opportunity to have someone who can advocate alongside them or on their behalf. This pressure can bring extra resources into the system as it has done in the field of education. However there is presently limited scope for parents to enlist the help of advocates.

Consultation with children and young people

Recent legislation and guidance across education, health, leisure and social services strengthens the expectation that professionals will consult with children and young people about the decisions that affect them. This can prove harder when the child has a disability but various studies have investigated this issue and provided guidance on ways of overcoming communication difficulties (e.g. Kelly et al, 2000). However much remains to be done especially of those children and young people with multiple disabilities.

Entitlement to health and social services

Demand for family support services often exceeds supply but the procedures for allocating services to families and children are often not transparent. Moreover when services are spread too thinly it is questionable the amount of benefit that families actually receive. There has been a dearth of research and even auditing of family support services. Nor can access to these services be determined solely on the characteristics of the child with the disability; parental and family needs must also be taken into account.

Direct Payments

For older teenagers the extension of Direct payments to families opens up new possibilities for families to obtain the services they feel are best suited to the needs of their families. (This is proposed to happen in Scotland). The development of voucher schemes and service brokerage have also been proposed as ways of giving more power to parents over the services they access. The English White Paper – Valuing People – gave considerable support for Direct Payments.

Inclusion

Increasingly parents expect services to be available in ordinary settings; notably mainstream preschool and school settings or in mainstream leisure settings (Thompson, Taylor & McConkey, 2000: O'Connor, Hartrop & McConkey, 2003). This has implications for health services in particular, in that more of the therapies and specialist nursing services will need to be provided in mainstream settings rather than in special schools which tends to be the predominant model at present in Northern Ireland, although this appears to be less so in other parts of these islands.

Short Breaks - Leisure Activities

Many parents seek breaks from the caring role but prefer those that offer their children a perceived benefit. After-school clubs, evening and weekend activities need to be more widely available. Family-based, short break schemes are also seen to offer benefits to the child (Prewett, 2000) as can domiciliary support workers when they facilitate the child participation in community activities or outings. If provision is provided in a residential settings, families prefer these to be in small, homely and local accommodation (McConkey, Truesdale and Conliffe, 2003: see Part 2).

Transitions

The period from 14 to 25 years has been characterised as a particularly difficult time for family carers and the young person (Ward et al, 2003). Among the proposals for improvements is the development of a multi-agency transition plan; the provision of a named worker to co-ordinate the service changes and greater choice of post-school options (see Chapter 4).

Autistic Spectrum Disorders, ADHD and mental health needs

Increasing numbers of children are being diagnosed with these two conditions. This places increased demands on already under-developed health and social services for families. The emphasis is currently on the need for early identification and intervention services but this has yet to be realised in many localities (Moore et al, 1999). The debate is whether services need to be designated specifically for these syndromes or whether the needs of the children and their families can be met by existing generic Child & Family Services. This is thought unlikely in the immediate future given the dearth of expertise within these services and the pressures they are under although this could well be a longer term goal. The conclusion reached in a recently completed UK Review by the Foundation for People with Learning Disabilities (2002) was that an augmented Child and Adolescent Psychiatry service would best provide the specialist help required by children and young people with additional mental health needs. They also recommended closer working between Child and Adolescent Psychiatry and learning disability services.

High quality staff training

Opportunities for staff in health and social services to be trained in family-centred approaches has been limited. This needs attention in both pre-service and in-service training. Supervised practice should form a core element of such training alongside the participation of parents and young people with disabilities as trainers.

Involvement of parents in service planning

Mechanisms need to be found so that the voice of parents is heard in planning forums at local, regional and national levels (Department of Health, 2001).

Circles Network (2004) have recently developed a leadership and empowerment programme aimed at training and supporting parents to become Partners in Policymaking. This has built on experiences in the USA and UK and a course has recently been completed in Northern Ireland. The aim is to develop "community leaders who will work with others to build a fairer and more just society for all by … working with others to change things locally and nationally". Although it is early days to assess the impact of this initiative is does attempt to redress the imbalance of information that is available to parents and opposed to professionals.

Re-organisation of services

Some have proposed a radical overall of existing services if multi-professional, family-centred services for children with disabilities in particular is to be attained. Within Britain, some local authorities have merged their social services, housing and education departments and forged partnerships with primary healthcare with a view to providing one-stop, local services for families (Russell, 2003) and Government is considering the establishment of 'Children's Trusts' with a remit for service delivery. These arrangements would provide for the joint funding of services as well enabling professionals to work in partnership under common management structures. Voluntary agencies are also well placed to provide integrated services particularly in the preschool years.

Conclusions

Family-centred services for children with disabilities are slowly becoming more of a reality in our education, health and social services. This has been triggered by parental lobbying allied with increasing recognition by professionals of the complexity of creating an ordinary family life for children with disabilities. Present services are bound by bureaucratic and rigid operating procedures as much as by a lack of monies and suitably trained personnel which are required to create a new paradigm in responding to the needs of families – and not just to the disabilities of the child.

References

Andersson. (1993). Depression and Anxiety in families with a mentally handicapped child. *International Journal of Rehabilitation Research*, 16 (3), 165-169.

Baker B. (1988) Evaluating parents training. *Irish Journal of Psychology*, 9, 324-345

Barr, O. (1999) Supporting families : reflecting on tacit messages. *Journal of learning disabilities for nursing, health and social care*, ,3, 121-122

Bevan, M. (2002) *Housing and disabled children: The art of the possible*. Joseph Rowntree Foundation: Findings November 2002.

Booth, C.L. & Kelly, J.F. (1999). Child care and employment in relation to infants' disabilities and risk factors. *American Journal on Mental Retardation*, 104, 117-130.

Carer's National Association, 2000.

Carpenter, B. (2000). Sustaining the family: meeting the needs of families of children with disabilities. *British Journal of Special Education*, 27, 3, 135-143.

Circles Network (2004). Partners in Policymaking. www.circlesnetwork.org.uk

Cotterill, L., Hayes,L., Flynn, M. and Sloper, P. (1997). Reviewing respite services: some lessons from the literature. *Disability and Society*, 12, 5, 775-788.

Department of Health (2001a) *Valuing People*. London. HMSO.

Department of Health (2001b) *Family Matters: Counting Families In*. London: DoH.

Dunst, C.J., Trivette, C.M., & Cross, A.H. (1986). Mediating influences of social support: Personal, family, and childhood outcomes. *American Journal of Mental Deficiency*, **90**, 403-417.

Foundation for People with Learning Disabilities (2002) *Count us in- report of an inquiry into the needs of young people with learning difficulties who have mental health needs*. London: Foundation for People with Learning Disabilities

Glendinning, C. (1992). *The costs of informal care: Looking inside the household*, London, HMSO.

Harrison, N. (2000). Respite care services for adults with learning disabilities: Carer stress and satisfaction with services. *Masters Dissertation in Applied Psychology*. University of Ulster.

Hastings, R.P., Allen, R., McDermott, K. and Still, D. (2002) Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 269-276

Hatton,C., Akram.J., Robertson, J., Shah, R. and Emerson, E. (2003) The disclosure process and its impact on South Asian Families with a child with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16, 177-188

Kelly, B. & Monteith, M. (2003) Supporting Disabled Children and their Families in Northern Ireland. National Children's Bureau Report

Kelly, B., McColgan and Scally, M. (2000) Chance to say: Involving children who have learning disabilities in a pilot study on family support services. *Journal of Learning Disabilities*, 4, 115-127.

McConkey, R. and Adams, L. (2000) Do short breaks services for children with learning disabilities match family needs and preferences? *Child: care, health and development, 26, 429-444*

McConkey, R. and McAteer, D. (1999) The contacts which families and children with learning disabilities have with health and social services. *Child Care in Practice, 5 (2), 67-73.*

McNally, S., Ben-Shlomo, Y. and Newman, S. (1999) The effects of respite care on informal carers' well-being: a systematic review. *Journal of Disability and Rehabilitation,* 21, 1-14.

Maes, B.,Broekman, T.G.,Dosen, A., and Nauts, J. (2003) Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research*, 47, 447-455

McKeown. P., Piggot, M., Burghri, S. and McConkey, R. (2001) An evaluation of the Mencap Family Adviser Service in Northern Ireland. *Child Care in Practice* , 7, 273-287

Moore, K., McConkey, R., Sines, D. and Cassidy, A. (1999) Improving diagnostic and assessment services for autistic spectrum disorders. *Early Child Development and Care*, 154, 1-11.

O'Connor, U., Hartrop, B. and McConkey, R. (2003) *Parental attitudes to the statutory assessment and statementing procedures on special educational needs*. Belfast, DENI

Prewett, B. (2000) *Committed to caring: The views of short break carers for children who are 'hard-to-place'*. York: York Publishing Services.

Russell, P. (2003) Effective family support: message from research and practice in UK. Paper given at 4th European Congress on Mental Health and Mental Retardation: A lifespan multidisciplinary approach. Rome.

Redmond, B., and Richardson, V. (2003) Just getting on with it: Exploring the service Needs of mothers who care for young children with severe profound and life-threatening intellectual disability, *Journal of Applied Research in Intellectual Disability*, 16, 205-218

Singhi, P.D., Goyal, L., Pershad, D., Singhi, S. & Walia, B.N.S. (1990). Psychosocial problems in families of disabled children. *British Journal of Medical Psychology*, 63, 173-182.

Sloper, P. (1999) Models of service support for parents of disabled children. What do we know? What do we need to know? Child: Care, Health and Development, 25 (2), 85-99

Stores, G. (1992). Annotation: Sleep studies in children with a mental handicap. Journal of Child Psychology and Psychiatry, 33, 8, 1303-1317.

Thompson, B., Taylor, H. and McConkey, R. (2000) Promoting inclusive play and leisure opportunities for children with disabilities. *Child Care in Practice*. 6, 108-123

Twigg, J. & Atkin, K. (1994). *Carers perceived: policy and practice in informal care*. Buckingham: Open University Press.

Ward, L., Heslop, P., Mallett, R., and Simons, K. (2003) Transition: The experiences of young people with learning disabilities and their families in England. *Tizard Learning Disability Review*, 8, 19-28.

Williams V and Robinson C (2000) *In their own right*. Bristol: The Policy Press.

Chapter 6:

The Physical Health of People with a Learning Disability.

Overview

An increasing number of people with a learning disability are living long and healthier lives. Greater numbers of children with complex health needs are now living into adulthood. The changing demography among the population of people with a learning disability is altering to reflect that of the general population with increasing life expectancy for greater numbers of people.

In order to maximise the benefits to people with a learning disability it is necessary that their right to equity of access to healthcare be recognised. Avoidable deteriorating physical health should not restrict the increasing opportunities for people with a learning disability. However research evidence in Northern Ireland and further afield shows that people with a learning disability have high levels of unmet health need and difficulties in accessing primary and secondary health services.

This chapter aims to provide an analysis of current research into the health of people with a learning disability in Northern Ireland and set it within in the wider context of research undertaken elsewhere within the United Kingdom and internationally.

It is structured in four main sections, namely:

Section 1 defines physical health and equity of access to health care

Section 2 considers the physical health status of people with a learning disability.

Section 3 summarises the reported experience of people with a learning disability and their families

Section 4 examines the factors in the wider environment that may impact on the use of health services by people with a learning disability.

Section 1: Defining physical health

A range of definitions and perspectives

Most people have their own definitions of health and what is means to be healthy. However a brief discussion with colleagues will often show that considerable differences exist among people about what it means to be healthy. Personal definitions of health are important to individuals and can vary widely, although they usually fall into one of two categories, those involving the presence of physical abilities and those that focus on the absence of illness. At a policy and service level the use of agreed definitions of health assists in providing some commonality and transparency about what is meant by the use of the term.

The mostly widely accepted and longstanding definition of health is that of the World Health Organisation which was incorporated within Investing for Health (DHSSPS, 2002). This emphasises that health is a broader concept than physical health which must also include mental and social well-being. It also highlights how health is about the presence of attributes and abilities (a positive concept) and that the absence of ill health does not of itself constitute the presence of health.

Box: The evolving definitions of health

'health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO, 1946)

'the extent to which an individual or group is able to, on the one hand realise aspirations and satisfy needs; and on the other hand, to change and cope with the environment. Health is therefore seen as a resource for everyday life, not an object of living; it is a positive concept emphasizing social and personal resources, as well as physical capacities' (WHO, 1984 in Naidoo & Wills, 1994, p.21)

'a person's optimum state of health is equivalent to the set of conditions which fulfil or enable a person to fulfil his or her realistic chosen and biological potentials'. (Seedhouse, 1986, p.61)

More recent attempts to define health have identified the functionality of health (Fleming, 1999) and built on the original WHO definition to include the importance of recognising that health influences the degree to which an individual can cope within and adapt to their environment and it may be limited by biological potentials and personal choice (Box). This is not to restrict the definition of health nor identify people who may be considered unhealthy, but rather to show how people with perhaps limited physical or mental abilities can still achieve a level of health within these apparent limitations.

This message is echoed by Fleming (1999) in stating that physical health status "is aggregated by factors such as genetic inheritance, the functioning of the major body systems, the physical fitness to perform those functions which are necessary for each individual and the presence or absence of physically disabling factors." He goes on to state that "*It should not be assumed that the presence of a disability necessarily lowers* *the health status – individuals can still achieve optimum physical health status, for them, within the constraints of their disability*' (p231).

Building on the need to measure health functioning the WHO launched the International Classification of Functioning, Disability and Health (ICF) in 2001. This sought to move away from defining health on the basis of mortality rates and focus on how people live with their health conditions and how their situations can be improved to result in them leading more productive and fulfilling lives (WHO, 2001). In essence, it did not seek to define health but rather to provide an internationally agreed classification for measuring health.

The classification system is structured in two parts, firstly Functioning and Disability which includes the components of Body functions and Structures as well as Activities and Participation. The second part covers Contextual Factors and includes the components of environmental factors and personal factors.

Within each component health and health related domains have been identified together with relevant constructs that provide a framework for the assessment of an individual's health. It seeks to provide a classification system based on the 'components of health' rather than the consequences of disease. It is expected that this classification system will become integral to how functioning, health and disease are measured in the years to come and will supersede currently used definitions.

The message in the newer functional definitions and classifications is that all people should be considered to have the potential to achieve an optimum level of health for them and be involved in deciding what this involves. Therefore the presence of a learning disability should not result in a stereotype of the inevitability of poor physical health.

Factors that influence physical health

The factors may contribute to poorer heath have been described as 'complex and inter related' (DHSSPS, 2002). The principal factors thought to impact on one's health can be grouped under the broad headings outlined in Table 1.

All of these factors potentially impact on the health of people with a learning disability as much as people without a learning disability. Indeed some may have more prominence in the live of people with a learning disability when considering the growing evidence of harassment of and crimes against people with a learning disability within the UK that has included data collected in N Ireland (Mencap, 1997).

Similar to members of the general population, the limited opportunities available to some people with a learning disability to make informed decisions about their lifestyle due to restricted accessible information, poverty or other people making decisions about them may result in the development and maintenance of a lifestyle that does not provide good physical health (DHSSPS, 2002).

Table 1: Broad areas that have been identified as having a potential impact on health (DHSSPS, 2002)

- Disadvantage and social exclusion
    - Poverty
    - Unemployment
    - Low educational achievement
    - Poor social and community environment (including crime)
- Living conditions
- Working conditions
- The wider environment
- Individual's behaviour and way of life
    - Smoking
    - Drug misuse
    - Alcohol
    - Physical activity
    - Food and nutrition
    - Sexual health

Further to the factors listed in Table 1, many people with a learning disability will have additional difficulties that may arise from physical or sensory impairment, reduced communication abilities, particularly in relation to written materials.

For some people, the presence of a specific syndrome or related impairment that is associated with the origins of their learning disabilities may also increase their risk to physical ill health (co-morbidity), although actual physical ill health is not an inevitable outcome. For instance, examples include the increased risk of respiratory problems among people with Down syndrome, injuries that may arise if an individual with epilepsy has a seizure, or as a result of self injurious or other challenging behaviours (DoH, 1995).

The increased prevalence of mental health problems among people with a learning disability will also present additional difficulties for people in maintaining an optimum level of physical health (Emerson et al., 2001).

Neurological and musculo-skeletal abnormalities existing in the learning disability population also require effective management through adequate service provision to ensure that physical impairments are not compromising optimum physical health attainment.

Equity of Access to health care

The values underpinning 'Investing for Health' (DHSSPS, 2002) are:

- Health is a fundamental human right
- Policies should actively pursue equality of opportunity and promote social inclusion
- Individuals and communities should be fully involved in decision making on matters relating to health

- All citizens should have equal rights to health, and fair / equitable access to health and health information according to their needs.

Central to the achievement of health is that right to equitable access to health and health information as noted above. An analysis of this concept defined equity of access to healthcare as the '*the moral right to have an equal opportunity, to enter and / or avail of a quality service, in order to meet a perceived health care need*' (Sowney & Barr, in press).

It recognised that the achievement of equity of access is dependent on the presence of antecedents including people with a learning disability having a desire to feel healthy, a perceived unmet health need, a previous knowledge of who can help, the ability to make comparisons or judge and a feeling of trust. It is argued that the presence of equitable of access to health care can be was assessed by the degree to which people with a learning disability:

- Feel empowered by knowing that they have the right to avail themselves equally of the service
- Have opportunities to seek and gain access to a service within an equitable time frame
- Have confidence in the service provider
- Perceive a sense of fairness.

The above analysis demonstrates that is not enough for health services to exist, but that action needs to be taken to facilitate access to healthcare and that the services received must be at least of the quality provided to other citizens.

Physical health as a dynamic process

In using the term health status Fleming (1999) seeks to show that an individual's health is not static, but rather it is a dynamic and changing process. All components of one's health can be influenced by a range of factors noted by Fleming such as genetic factors, physical fitness and physically disabling factors. Furthermore a number of broader influences which are often present in the lives of people with a learning disability such as disadvantage and social exclusion, poor living and working conditions, an individual's behaviour and way of life, together with other aspects in the wider environment can impact on one's health (DHSSPS, 2002).

Changes in the physical health status of people with a learning disability have become more evident in the past decade as increased research has been undertaken in this area. Broadly speaking the major causes of ill health among people with a learning disability are similar to that of the general population, in so far as coronary heart disease, stroke; cancer; sexual health; accidents, diabetes, thyroid problems, and respiratory problems are major causes of ill health (DoH, 1995; Horwitz et al., 2000). Tumer and Moss (1996) also reported that people with a learning disability required attention to their health in respect of congenital heart problems, infections, visual and hearing impairments, skeletal problems, movement disorders and dental health.

However on further examination the research indicates that differences do exist in the physical health status of people with a learning disability in a number of areas. These relate primarily to a high level of unmet health need and some variation in the prevalence of conditions among the population of people with a learning disability.

Conclusions

The main messages about health can be summarised as follows

- Health is more than the absence of ill health or disease.
- Many factors both biological and social impact on health.
- Health is a fundamental human right.
- People with a learning disability are not inevitability unhealthy and should be facilitated to achieve and maintain an optimum physical health status.
- Equity of access to health care for people with a learning disability will require action to facilitate the presence of the appropriate antecedents and ensure that the outcomes for them are of a comparable quality to those for other service users.
- Regular monitoring of a person's health status is important to maintain their optimum health.

Section 2. The physical health status of people with a learning disability

Over the last ten years a number of research projects have been undertaken in Northern Ireland into the health of people with a learning disability. These involved health screening and assessment of the effectiveness of interventions to achieve health gain among people with a learning disability.

Health screening for people with a learning disability

Services for people with a learning disability living within Northern Ireland were among some of the first in the United Kingdom to identify the scale of unmet health needs of people with a learning disability. The first project commenced in Down Lisburn Trust in 1992 (Meehan et al., 1995).

Two models for health screening of people with a learning disability have been undertaken within Northern Ireland. The initial approach was to set up specific health screening events for people with a learning disability within specialist services, such as day services. This approach used within Down Lisburn Trust involved community nurses - learning disabilities together with a general practitioner and at times a dentist undertaking a health check for people with a learning disability within specialist learning disability services. Between 1992 and 1999 health checks were completed for 398 adults and 164 children (Marshall et al., 2000).

The second approach used within Homefirst Trust and North & West Belfast Trust also involved collaborative working between community nurses – learning disabilities and general practitioners; however the health screening was completed within a local health centre (Leggett, 2001) or the person's local general practitioner surgery (McConkey et al., 2003). These projects both run over two years during which time health checks were completed with 61 and 122 people respectively.

Overall the data from these projects presents a picture of considerable unmet health needs among people with a learning disability. Results indicated that the majority of people with a learning disability had one or more previously undetected health needs identified. These ranged in severity from skin disorders, to endocrine disorders and abnormalities requiring further investigation and treatment (Table 2).

Table 2: Overview of the findings of unmet health needs during health screening projects for people with a learning disability in Northern Ireland

(Meehan et al., 1995, Barr et al., 1999; Leggett, 2001; Marshall et al., 2003; McConkey et al., 2003)

Areas of health screen	Examples of conditions detected
Blood pressure	Hypertension, hypotension
Weight	Obese, overweight, underweight
Oral Health	Poor oral hygiene, loose teeth, tooth decay, gum infection
Skin / Hair	Dry scalp, dandruff, varicose veins, eczema, psoriasis, acne
Urinalysis	Glucose, protein and blood present
Testicles	Undescended, swollen underdeveloped

Breasts	Inverted nipple, skin tags, breast lumps and male breast enlargement
Feet	Corns, verucca, fungal infection, damaged nails / nail beds, poor circulation
Ears	Excess ear wax, hearing difficulties
Eyes	Cataracts, reduced vision
Blood tests	Hypothyroidism, diabetes

Comparative analysis of the results from health screening for people with Down syndrome (n=76 people) and people with a learning disability who did not have Down syndrome (n=297) showed that people with Down syndrome were significantly more likely to have reduced vision and skin problems. However it also demonstrated that although a higher number of people with Down syndrome were overweight (60% compared to 52%) the difference was not statistically significant (Barr et al., 1999). In comparing the health status of adults and children with a learning disability Marshall et al., (2003) reported that many of the early indications of later health problems were present in younger children. These authors also identified that teenagers with a learning disability were significantly more likely to be obese than children with a learning disability who were under 12 years of age.

The findings of health screening among people with a learning disability within other parts of the United Kingdom and internationally reveals a consistent pattern of previously undetected health needs across a similar range of areas. As health screening has become more comprehensive further difficulties have also been reported in respect of health needs related to incontinence and gastrointestinal problems including gastro-oesophageal reflux and hiatus hernia (see Health Evidence Bulletins Wales – Learning Disabilities 2001)

The evidence from health screening research clearly shows a high level of unmet health need among people with a learning disability as well as establishing that among the population of people with a learning disability some groups of people may be at increased risk of particular health problems.

However there is also concern that people with a learning disability do not access the specialist screening services available to the wider community such as cervical screening, prostate cancer screening or mammography. Recently in England the National Screening Programme has made special efforts concerning cervical screening for women with a learning disability.

Table 3: Overview of the findings of health screening projects within the other areas of the United Kingdom and internationally for people with a learning disability in Northern Ireland

(Turner & Moss, 1996; Horwitz et al., 2000; Hunt et al., 2001; Cassidy et al., 2002; Hatton et al., 2003)

Area of Health Screen	**Examples of conditions detected**
Optical / visual impairments	(reduced vision, need for prescription glasses, cataracts, eye infections)
Ear, Nose and Throat	(hearing loss, ear wax)
Dermatology	(eczema, psoriasis, dry skin)

Mobility problems	(arthritis, obesity, foot problems)
Dental health	(problems with teeth, gums and mouth ulcers)
Sexual health	(menstrual problems, testicular and breast anomalies)
Cardiovascular	(obesity, hypertension)
Endocrine	(diabetes, thyroid problems)
Gastrointestinal	(pain & discomfort, reflux problems, peptic ulcers, constipation)
Continence problems	(reduced continence, urinary tract infections, pain & discomfort)

Prevalence rates of physical ill health compared to members of the general population

It is clear that as the age of death of people with a learning disability increases the pattern of morbidity and mortality among this group of people is in many ways becoming similar to that of the general population. This is reflected in the reported increase in deaths arising from cardiovascular disease, stroke, and cancers while at the same time there has been a reduced in the number of deaths arising from infections (Hatton et al., 2003).

Much debate has taken place in respect of the incidence of ill health among people with a learning disability in comparison to that of the general population. Two main strategies have been used to answer this question; the first approach has involved the inclusion of control or comparison groups within research projects investigating the health of people with a learning disability. In the main these studies have tended to focus on hearing and visual impairments, conditions of the nervous system, skin disorders and obesity. These conditions are more 'visible' and data from observation and measurement can usually be collected to support the presence of these conditions without the need for most intrusive investigations that other conditions may need to confirm their presence.

In undertaking a review of comparative studies on the health problems of people with a learning disability Jansen et al. (2004) located eight studies that they considered robust and included control groups undertaken since 1995. The evidence from these studies does indicate that people with a learning disability have increased prevalence rates for epilepsy, diseases of the skin, sensory loss and increased risk of fractures.

A second approach for conditions that require more intrusive investigation or have a lower frequency has been the comparison the reported rates of particular conditions and illness among people with a learning disability with national prevalence rates for that condition. The most comprehensive review in this area has been undertaken in relation to cancer among people with a learning disability. The authors concluded that although the overall prevalence rates of cancer among people with a learning disability are similar to that of the general population there is evidence of an increased prevalence of particular types of cancer among people with a learning disability (Hogg et al, 2000). Cancers of the stomach and oesophagus, as well as testicular cancer have been reported at rates higher than those present in the general population.

Conversely people with a learning disability appear to have lower rates for lung, breast, urinary tract and prostate cancers (Duff et al., 2001; Patja et al., 2001; Cooke, 1997).

Oral Health

Research in England and USA has suggested that the oral health status of people with a learning disability is worse than the general population with poorer oral hygiene, higher untreated diseases and more extractions (Nunn, 1987, Gordon et al, 1998). There is evidence too that people moving from institutional care into community settings have increased decay levels as their stay in the community increases despite equity of access and an initially lower prevalence of caries than in the general population (Tiller et al, 2001).

The primary reasons advanced for poorer oral health is a difficulty in accessing dental health services either because of the lack of suitable provision or the increased anxiety experienced by this client group to dental treatments (Kenny, 1999). Matthews et al (1993) reported low confidence among newly qualified dental graduates in treating patients with special needs.

A survey of over 70 general dental practitioners in Northern Ireland found that fewer than 10% of respondents had received any form of training to assist them in managing these patients (Barr et al, 2003).

Recent initiatives by the British Society for Disability and Oral care along with the Faculty of Dental Surgery of the Royal College of Surgeons are designed to provide improved clinical care pathways and local standards for oral healthcare. Community Dental Services are seen as having a particular function in meeting the particular needs of this client group (Hay, 2003).

A difficult issue at present is the requirement for general anaesthesia to be carried out only in Hospital. This has resulted in long-waiting lists for treatment. There is growing interest in the use of sedation techniques as an alternative (Hay, 2003).

Oral health promotion is also vital with this client group and carers in particular have a key role to play in this. The development of educational materials targeted at people with a learning disability is particularly necessary and the NHSSB have produced some excellent new resources.

Factors contributing to poorer health status

The physical health status of people with a learning disability may be directly impacted upon by broad influences that can affect all members of the general population. The health of people with a learning disability is also impacted upon by specific risk factors that may arise due to the presence of a learning disability. Finally, the delay in detecting existing health needs and the limited effectiveness of response to these health needs will contribute to the poorer health status of people with a learning disability.

Social and environmental influences on health

It is recognised that the health of any individual, including people with a learning disability will be impacted upon by a number of key factors, namely:

- Disadvantage and social exclusion
- Living conditions and economic wellbeing
- Working conditions

- The wider environment
- Individual's behaviour and way of life (DHSSPS, 2002)

The influence of several of these factors may be stronger in the lives of people with a learning disability, for instance, these may be a greater impact from disadvantage and social exclusion arising from higher rates of poverty, unemployment and low educational achievement (Band, 1998; Emerson et al., 2003). Limited opportunities for involvement in local community activities arising from a number of factors including lack of awareness of these opportunities, dependence on others for transport (often older carers) and the costs involved can result in people with a learning disability leading a more sedentary lifestyle.

Furthermore, poor nutrition and the long-term use of a large number of medications (polypharmacy) have been identified as particular risk factors among people with a learning disability (Beange, 2002).

The majority of people with a learning disability in Northern Ireland live in community settings with either parents, family members or in a range of residential facilities. The impact of living 'under supervision' may result in a dependency on others to identify health problems and to meet their health needs. Therefore the awareness and views of carers (family and professionals) will be an important influence in accessing healthcare. If carers do not have the knowledge and skills to recognise the indications of poor health, or assume that difficulties are related to the presence of learning disabilities and therefore not amenable to treatment health services may not be accessed. As a consequence people with a learning disability may find it more difficult to achieve the antecedents of having a desire to feel healthy, a perceived unmet health need, a previous knowledge of who can help, the ability to make comparisons or judge and a feeling of trust considered necessary for equity of access to health care.

Co morbidity: the presence of a learning disability as an additional risk factor

It is not inevitable that people with a learning disability will develop ill health; however for some people with a learning disability the presence of particular syndromes or conditions associated with their learning disabilities may increase their likelihood of having physical health problems.

For instance, people with Down syndrome are recognised has having significantly more health difficulties in the areas of vision and hearing (Barr et al., 1999) and may also develop further difficulties related to cardiovascular problems, resistance to infections and their immune system (Stratford & Gunn, 1996). Many other syndromes present among people with a learning disability have associated health problems; this does not make the ill health inevitable, but highlights the need for regular monitoring and treatment (O'Brien et al., 2002; Lennox, 2002).

The presence of learning disabilities either as the result of a specific syndrome or of unknown origins is associated with increased prevalence of epilepsy, together with physical and sensory impairments (Jansen et al., 2004). The presence of these conditions may further increase the risk of sustaining physical injuries. This can directly impact on both the opportunities that people have for physical activity and the independence they develop. Furthermore increasing numbers of people with a learning disability, children, young adults and older people who require intensive nursing care and technological support arising from the presence of complex health needs have increased risks of infection and respiratory difficulties (Wake, 2003).

Delay in detecting and limited effectiveness of responses to existing health needs

Research within Northern Ireland has reported a high degree of previously undetected health needs among people with a learning disability. These findings are consistent with those reported elsewhere within the United Kingdom and internationally (Horwitz et al., 2000; Hunt et al., 2001; Cassidy et al., 2002; Hatton et al., 2003).

The delay in identifying and responding to these unmet health needs increases the risk of future more serious health problems arising. For instance many of the unmet health needs are contributing factors to the presence in those who are obese of conditions, such as, hypertension, cardiovascular disease, stroke and diabetes. In addition the presence of pain, reduced mobility and the discomfort that may arise from untreated skin conditions may further reduce opportunities for inclusion in activities that promote health.

Finding unmet health needs among people with a learning disability over a number of years lends supports to a conclusion that either little has been done in the past to respond to the situation or that the action which has been taken has been ineffective. Marshall et al. (2003) highlighted the limitation of health screening in achieving health gain by demonstrating that in an attempt to follow up 122 people three months after being identified as overweight at heath screening only 70 responded to questionnaires.

Furthermore, 29% of those people reported that no further action had been taken after the referral from the health screening service to parents and carers. For 35% of people a variety of actions including cutting down on food, taking exercise, eating more healthily and investigating for thyroid problems were reported, however only 2% were identified as actually achieving a weight loss. These results are in contrast to the weight loss achieved by 30% of people who completed a series of between 6-8 health promotion sessions.

A limitation of the some of the health screening research in Northern Ireland is that although it reports the number of unmet needs identified and referrals made to other services, there is no clear indication of the action that these other services subsequently take and the outcomes achieved for the person with a learning disability (Meehan et al., 1995; Barr et al., 1999; McConkey et al., 2003). Therefore it is not possible to demonstrate how the identification of an unmet health need and the subsequent action resulted in health gain for many people with a learning disability, whilst the available evidence suggests that only limited health gains were achieved.

Barriers to accessing heath services

A number of factors have been identified as potential barriers for people with a learning disability having equity of access to health care services. These include factors listed below that may arise from the presence of learning disabilities, the previous experience of people with a learning disability, the abilities of professionals, the structure of services and negative attitudes towards people with a learning disability (Meehan et al, 1995; Baxter & Kerr, 2002).

- Fears of unknown places and investigations, leading to non co-operation
- Challenging behaviour, such as hyperactivity, shouting or self injurious behaviour
- Difficulties in meeting certain social expectations, such as waiting in queues, behaving appropriately in reception areas and interacting with health service staff

- Difficulties of professionals in assessing needs owing to insufficient training, equipment, or motivation, or problems owing to physical impairments of people being examined / treated
- Inability to communicate needs / symptoms, such as pain, discomfort, reduced physical or sensory ability
- Difficulty in reading and understanding published material or technical terms
- Lack of specialist health screening for people with a learning disability
- Failure of carers or people with a learning disability to recognise the need for health screening and reluctance to seek medical or nursing attention when required
- Assumptions that any changes in behaviour or health status are due to the presence of learning disabilities.

Conclusions

In summary then,

- Research evidence from a number of studies undertaken in Northern Ireland demonstrates a wide range of unmet health needs among people with a learning disability
- Comparative research studies support the view that people with a learning disability have higher prevalence rates of health needs in relation to hearing, vision, conditions of the nervous system (e.g. epilepsy), skin disorders, obesity and some cancers (oesophageal, stomach and testicular).
- The physical heath of people with a learning disability is impacted upon by the same broad factors that affect other members of the general population. In addition, people with a learning disability may encounter further challenges to their heath arising from co- morbidity (due to the presence of learning disabilities), as well as the delay in identifying unmet health needs and the limited effectiveness of responses to these.
- Health screening of people with a learning disability can assist identify unmet physical health needs, but limited effectiveness in achieving physical health gain for people with a learning disability. To be effective specifically targeted actions, usually involving collaboration between primary care / acute general hospitals and specialist learning disability services need to be taken in order to facilitate people with a learning disability to achieve health gain.

Section 3: People with a learning disability and their families accessing mainstream health care

People with a learning disability should have access to all mainstream health services provided to other members of the Northern Ireland population in the form of primary care services and acute hospital services. This section provides an overview of the reported experience of using primary care and acute general hospital services. In addition, some people with complex physical health needs may receive services from community and hospital based specialist learning disabilities services.

Primary Care

General Practitioner Services

The majority of people with a learning disability live with parents, with other family members or a range of community based accommodation ranging from residential and nursing homes to independent and supported living. Therefore for the majority of people with a learning disability in Northern Ireland their general practitioners are the professionals responsible for providing general medical services to them. All people with a learning disability should be registered with a general practitioner and a dentist.

No studies have been undertaken in Northern Ireland which provide definite details of how many people with a learning disability are registered with a General Practitioner or Dentist, nor do any figures exist on the extent to which people with a learning disability use these mainstream services and other associated screening services such as cervical screening, visual screening, or hearing assessment (Band, 1998).

In a survey of 102 general practitioners and 35 practice nurses / nurse practitioners in the WHSSB area which asked people for their perceptions, 37% of general practitioners and 20% of nurses felt people with a learning disability used the practice as frequently as people who do not have learning disabilities, whilst 13% of general practitioners felt they used it more often. However the majority of nurses (63%) and 44% of general practitioners felt they used it less often (Finlay, 2002). Hatton et al. (2003) in an analysis of studies within the United Kingdom concluded that people with a learning disability visit their general practitioner as often as people who do not have learning disabilities; however they are less likely to receive regular health checks. It has also been reported that women with a learning disability are four times less likely to avail of cervical smear tests than other women in the general population and have a lower uptake of breast examinations.

Identifying people with a learning disability in primary care

Difficulties have also been reported in attempts to identify people with a learning disability on general practitioner registers for the purpose of health screening as no system exists for identifying people with a learning disability already on the practice register. In a survey within the WHSSB area 59% of general practitioners who were asked reported that they could not easily patients with a learning disability (Finlay, 2002). This can result in general practitioners identifying people they 'believed' to have learning disabilities with varying degrees of accuracy, at times causing annoyance and upset to those people identified as having a learning disability who did not have one (McConkey et al, 2003).

One approach to reduce these difficulties has been the collaborative working between primary care and specialist community nursing learning disability services. Through such collaboration it has been possible to refine and validate lists of people with a learning disability on practice registers, although this has not been without difficulties. In particular, issues relating to confidentiality and the sharing of information held by community nursing learning disability services.

These collaborative arrangements are presently in place as pilot projects within a few Trusts in Northern Ireland. Whilst in other Trusts further clarification is being sought about the sharing of information and the views of people with a learning disability. It is likely that some services will seek the permission of people with a learning disability prior to the sharing of information for the purpose of practice registers.

Acute General Hospital Services

Contact with acute general hospitals services

The current policy emphasis on inclusion and equity of access to health care including acute general hospitals is occurring at the same time the reducing capacity of specialist learning disability hospitals to provide complex health care for people with a learning disability who are acutely ill or injured (DHSS, 1995; NHSE, 1998). This means that people with a learning disability who develop physical health problems requiring hospital treatment will in the main receive this treatment within mainstream acute general hospitals. Due to the need for additional medical support, specialist dental services are no longer provided within learning disability hospitals and are provided within Day Procedures Units of several acute general hospitals in Northern Ireland.

However no studies have been completed that provide detailed information on either the extent of contact people with a learning disability have with acute general hospitals in Northern Ireland, or the quality of that experience. The first study in this area is nearing completion in the within the WHSSB area (Barr, 2004a). The project collected data from the parents and carers of 211 people who had contact with acute general hospitals in the WHSSB area between 2001-2003. It also held two focus groups with staff from within learning disability services and conducted a survey of 67 nurses within acute general hospitals. This project shows that between 2001-2003 a minimum of 211 people with a learning disability had contact with one of the three acute general hospitals in the WHSSB at least 525 times in total. Furthermore, over this time 106 people with a learning disability spent a total of at least 366 days in acute general hospitals. In addition to this, a large number of people attended hospitals for outpatient appointments several times over the previous two years.

The experience of contact with acute general hospitals

A summary of some preliminary findings from this on going project (Barr, 2004a) are provided below:

- People with a learning disability have regular contact with acute general hospitals
- Limited use is made of opportunities for the use of pre appointment / pre admission assessments and advance planning.
- At times limited steps are taken to accommodate the individual abilities and needs of the person with a learning disability.
- People with a learning disability are often excluded from key discussions and decision about their care

- Further training is required by Hospital staff in relation to requirements for obtaining informed consent from people with a learning disability
- Nursing staff have limited knowledge and skills in relation to working with people with a learning disability.
- The majority of parents and carers perceived the need to remain in hospitals for the duration of contact in order to ensure the person with a learning disability received adequate care and supervision.
- Some people with a learning disability will require ongoing additional support when in an acute general hospital if treatment is to be completed successfully.
- More effective liaison arrangements between acute hospitals and learning disability services need to be put in place.
- The is a need for further training of nursing staff to work with people with a learning disability in acute hospital settings.

The above findings are similar to those as outlined below which have been reported by people with a learning disability, their parents and carers from elsewhere in Northern Ireland and the United Kingdom.

The views of people with a learning disability

In 2002, a series of focus groups were held across Northern Ireland with people who have a learning disability which discussed a number of topics including health. The findings of this research reported that some people with a learning disability expressed fear due in part to uncertainty about what is happening and compounded by previous negative experiences during earlier contacts with acute general hospitals or health professionals (DHSSPS, 2002).

Several of these points have most recently been echoed within 'We have a dream' (DHSSPS, 2004) which emphasises the importance of health professionals communication; in the provision of information, listening to people with a learning disability and engaging directly with them rather than the parents / carer or professional who accompanies them.

Similar points have also been made by people with a learning disability who have participated in focus groups or individual interviews in England who have also reported a number of difficulties during their contact with acute hospitals. These have largely focused on being provided with limited information or explanations about what is going on and not feeling involved in the discussions and decisions that have taken place (Mental Health Foundation, 1996; Hart, 1999; Cumella & Martin, 2000). The confusion and fear that can arise from limited explanation and attempts to engage with people with a learning disability may result in difficulties in achieving informed consent and the required level of co-operation for the necessary investigations or treatment to be completed (Hart, 1999; Barr, 2004a).

Families and carers of people with a learning disability

Most available research in relation to the use of acute general hospitals by people with a learning disability has been undertaken with family members of people with a learning disability who have had contact with acute general hospitals. The findings show that parents and carers highlight long waiting times often in inappropriate environments with limited information prior to and during contact with the hospital. They perceived poor quality of care in relation to hygiene, nutrition and maintaining the safety of the person with a learning disability within an environment with limited opportunities for meaningful activities and in which the patient often becomes bored and restless. Furthermore limited forward notice of discharge, poor co-ordination of discharge and little or no support after discharge has been reported (Band, 1998; Fox &Wilson, 1999; Cumella & Martin, 2000; Whoriskey & Brown, 2002).

Parents have also reported the perceived need to stay in hospital during the period of contact. However little effort appears to be made to facilitate their stay in the hospital or make it comfortable, many parents have found the experience tiring and unpleasant (Fox & Wilson, 1999).

Specialist Learning Disabilities Services

The reconfiguration of specialist hospital services as assessment and treatment facilities together with the emphasis on inclusion in mainstream services will further reduce their role in the provision of nursing and medical care for people with a learning disability who develop physical health problems. At present the care provided to people with physical health needs in specialist learning disability facilities focuses on providing treatment for existing conditions rather than investigation of illness or treatment for major injuries.

As with primary care, people with a learning disability living in community settings receive services from District Nursing services, which is co-ordinated through the general practitioner. District Nurses have a similar role with people with a learning disability as they do with other members of the general population. In addition, community nursing learning disability (CNLD) services in Northern Ireland also have some role in providing support to people with a learning disability in relation to their physical health. The role of the CNLD is as a secondary service to provide additional support when mainstream services need further assistance to work with people with a learning disability.

In a recent survey of CNLD's within Northern Ireland, the provision of support in relation to physical health care made up 33% of the CNLD caseload and was a frequent reason for referral to CNLD services (Barr, 2004b). The work undertaken by the CNLD includes health promotion activities, the administration and monitoring of on going treatments, as well as facilitating access to primary and secondary health care services, with less time spent on clinical procedures such as dressings or other medical prescribed treatments.

It is expected that as other community nursing services develop, such as community children's nursing and the altering role of the Health Visitor that this will result in change to the role and work of the CNLD. Their role will shift further from the provision of direct care to people with a learning disability that of health promotion / health facilitation and promoting equity of access to mainstream healthcare services.

Conclusions

- Primary care and acute general hospital services have a key role to play in meeting the physical health needs of people with a learning disability.
- Difficulties exist at present in identifying the extent and nature of the use people with a learning disability make of primary care and acute hospital services.
- People with a learning disability, their families and nurses with services often report a difficult experience in using or providing service to people with a learning disability. The major difficulties relates to ineffective communication and limited confidence / knowledge / skills of the professional involved.
- The role of specialist learning disability services in providing investigation and complex treatment for the physical illness of people with leaning disabilities will reduce as specialist hospital reconfigure as assessment and treatment services.

Section 4: Factors impacting on the use of health services by people with a learning disability.

A number of factors appear to impact on the access to and use of health services by people with a learning disability. These include factors relating to the policy guidance / service structures as well as the views and actions of professionals in services.

Wider plans for healthcare in Northern Ireland

Despite the evidence that people with a learning disability have unmet health needs and at times higher prevalence rates for some physical health problems, there is limited attention to how these needs should be met within health policy documents at DHSSPS, HSSB and Trust level. Often the needs of people with a learning disability are included under the heading of 'vulnerable groups', together with a number of other groups. This approach fails to acknowledge the increased prevalence of some physical health problems and the particular support and facilitation people with a learning disability may have. It may also reinforce the stereotype of people with a learning disability as vulnerable and less able, which is not consistent with the emphasis on inclusion and supporting people to become empowered.

Another approach in wider plans for health care is to defer the work on the health needs of people with a learning disability through the inclusion of a 'comment' that further work needs to be done in relation to the needs of people with a learning disability, but no clear criteria set against which progress on this will be measured as has been undertaken other countries (Beange, Lennox and Parmenter 1999)

Limited Policy Guidance – who is responsible for services?

In the absence of clear guidance, major variation exists across Northern Ireland ranging some innovative health orientated projects to inaction. Key to several of the health focused projects in primary care services that have occurred in recent years has been 'fortunate alliances' among people who have a particular interest in the health of people with a learning disability. It was this level of interest and insight that drove forward several projects rather than the requirement that action was taken; therefore in the absence of interest no action is taken.

Whilst limited research has been undertaken with Northern Ireland in relation to people with a learning disability receiving acute general hospitals services, similar confusion over responsibilities appears to be present. It is often the situation when people with a learning disability are in acute general hospitals there is an expectation by general nursing services that additional support will be provided by learning disabilities services (at their expense). No formal structures appear to exist within Northern Ireland for accessing the degree of support required and again major variations can occur across Northern Ireland. The absence of clear guidelines and stated statutory responsibilities makes it more difficult for people with a learning disability to be treated with equity in acute hospital services.

Furthermore the lack of clearly stated responsibilities and requirements also makes it difficult to obtain on going funding for projects aimed at promoting the physical health of people with a learning disability. As a consequence the innovative projects that have produced the research noted earlier on this report no longer exist, including Healthcheck 2000 (Down Lisburn Trust) and Challenge 2000 (North & West Belfast) and Footsteps to Health (Homefirst Trust).

Not withstanding the fact that a review is presently underway and future policy will emerge from it, at present there is limited guidance on how health services should be delivered to people with a learning disability within Northern Ireland compared to other areas of the United Kingdom. Guidance in England, Scotland and Wales goes beyond broad statements of intent and identifies expected actions and responsibilities; it highlights the rights of people with a learning disability to access mainstream health services and the requirement for these services to take action.

This guidance also heightens the profile of the health needs of people with a learning disability within primary and acute care services as well as giving encouragement as to how this could be achieved (NHSE, 1998, 1999; DoH, 2003). The existing guidance was further strengthen by the requirements incorporated into the policy reviews which highlighted the right to health care, the need for registration with General Practitioners, health action plans and the development of health facilitation (SE, 1999; DoH, 2001). However within Northern Ireland no equivalent guidance exists and confusion remains about the main responsibilities of learning disabilities vis-à-vis mainstream health services to promote the physical health and meet the physical health needs of people with a learning disability.

Limited collaborative working between 'mainstream' and specialist services

Despite an 'integrated' health and social care structure within Northern Ireland, specialist learning disability services and the nursing staff who work within them appear to have limited formal links with primary care services, and do not appear to be part of primary care networks (Barr, 2004b). Similar limited collaboration between primary care and specialist learning disability services has been reported in England (Thornton, 1999; Giraud-Saunders et al., 2003).

Nevertheless well-developed examples of joint working between primary care and learning disability services have been reported in Northern Ireland and elsewhere (Barr et al., 1999; Martin, 2003; McConkey et al., 2003). However these are the exception rather than the norm. Health facilitators within services in England have a specific role in working between learning disability and primary care services, in effect providing the co-ordinating link (DoH, 2001). At present there is no equivalent to heath facilitators within Northern Ireland.

Whilst it is accepted by most general practitioners that they should meet the 'general medical needs' of people with a learning disability as part of their role, many do not believe they should be the ones providing on going heath screening for people with a learning disability (Kerr et al., 1996; Bond et al., 1997, Stein, 2000). Consequently, general practitioners do not usually undertake the role of co-ordinating the health care for people with a learning disability, which many see as the role of the specialist learning disabilities services.

Evidence is available from within Northern Ireland and elsewhere in the United Kingdom to show that when primary care and specialist learning disabilities do work collaboratively, the health status of people with a learning disability can be improved (Jones & Kerr, 1997; Martin et al., 1997; Marshall et al, 2001; McConkey et al, 2003;). However as experience has shown any progress that has been made within Northern Ireland services in relation to health screening or health promotion has relied of 'project' or non recurrent funding, and gains made may be quickly lost now that then projects have ceased.

Equally, collaboration between acute general hospital services and learning disability services has resulted in the development of several acute liaison nurses within the England and Scotland, at present no similar posts exist with Northern Ireland. These projects have been evaluated very successfully and have taken considerable steps towards achieving equity of access to healthcare for people with a learning disability (further information available at www.fons.org/networks/nnldn/a2a). In addition, acute liaison nurses have a role in providing training for staff as well as contributing to policy development, research and service development.

As thê preceding examples show, to be effective collaborative working needs must go beyond providing information to primary care and acute general hospitals services about what needs to be done, it must include practical support, training and sharing of information.

No clear idea of scale

Limited data exists about the frequency and reason for use of primary care services, nor does any clear data exists on the number of people with a learning disability availing themselves of screening services or making use of other clinics offered in primary care such as diabetes, asthma, or smoking cessation. In relation to acute general hospitals the only available data in Northern Ireland at present is contained in the draft report commissioned by the WHSSB (Barr, 2004a). Without more detailed information it is difficult to ensure that people with a learning disability have equity of access to services, or for planners to develop effective services to target people who may not be availing of existing services.

Within some Primary care services in Northern Ireland and England 'practice registers' of people with a learning disability are being developed. Such developments need the support of people with a learning disability and their families if these are to be effective. It is also important that clear guidelines exist in relation to the sharing of information between services and to provide people with the opportunity to opt in or out of such registers. Again collaborative working is required between learning disabilities and primary care / acute hospitals services in order to accurately identify people they believe to have a learning disability.

While a considerable body of research has been carried out within Northern Ireland it has been limited at times by being geographically localised studies, undertaken independent of each other, at times not building on the findings of previous work in Northern Ireland, and the interventions used may have been influenced by local service provision. These limitations make it difficult at times to directly compare the findings of the different studies with confidence, but do not detract from the convergence of findings which demonstrate the high level of unmet health needs and limited equity of access to health care among people with a learning disability in Northern Ireland, the UK and internationally.

In order to have a more complete picture of the health needs of people with a learning disability a co-ordinated approach needs to be taken to research across Northern Ireland, (perhaps with the use of pilot sites within an overall programme of research). This will provide a robust picture of the health status of people with a learning disability and the effectiveness of approaches to achieve health gain.

Views of professionals in mainstream services

Primary care

The views of professionals in primary care towards people with a learning disability and skills in communication have been identified as factors influencing the service provided to people with a learning disability (Singh, 1997; Band, 1998). In a survey of general practitioners in the WHSSB area, Finlay (2002) reported that 48% of general practitioners and 49% of nurses did not feel they had adequate training to work with people with a learning disability, while 20% of general practitioners and 17% of nurses felt that had. The remaining 32% of general practitioners and nurses were uncertain about their degree of preparation. The reported limited preparation and uncertainty about how to work with people who have a learning disability is consistent with the findings reported elsewhere in the United Kingdom (Kerr et al., 1996; Bond et al., 1997; Stein, 2000; Gill et al., 2002).

It has also been reported that general practitioners have generally positive attitudes towards people with a learning disability and whilst accepting their responsibility to provide general medical services for people with a learning disability believe health screening should be provided within specialist services (Gill et al. 2002). In a survey of GPs within Down Lisburn Trust although the majority of general practitioners felt health screening would be helpful for people with a learning disability, three quarters of those responding felt these would be better provided within specialist services. However after dealing with referrals from a contact with a health screening service provided by Community Nursing Learning Disability services, general practitioners reported being more favourable to undertaking health screening (McConkey et al. 2002). This would support the importance of collaborative working between specialist and primary care services and demonstrates that such collaboration could lead to improve equity of access to health screening in primary care settings.

Most surveys have taken place with nurses and general practitioners with little information on the views of the wide range of other professionals. However research evidence also show that people with a learning disability often do not avail of other health services within community settings (dentist, optician, audiologist, speech and language therapist, dietician) (Band, 1998). Given the reported impact and views of general practitioners and nurses on the availability and access to services, further research is needed to establish the views of other professionals and the impact these have.

Acute hospitals services

It is recognised that nurses within acute hospitals also report experiencing difficulties in working with people with a learning disability. Many report a limited degree of confidence and much uncertainty about what to do in working with people with a learning disability. This uncertainty in staff is also reflected in studies in Northern Ireland on the views of general nurses and other staff views towards caring for people with a learning disability in which they often reported limited knowledge, skills and experience in this area (Slevin & Sines, 1996; McConkey & Truesdale, 2000; Barr 2004a). Little research information exists in relation to the views of other professionals within acute general hospitals. However, one study undertaken in Northern Ireland which included 167 student therapists (mainly physiotherapists and occupational therapists) reported that therapists had significantly less confidence and felt more unprepared to work with people with a learning disability than the nurses in the study (McConkey & Truesdale, 2000).

Using focus groups with staff from general hospitals in one area in England, Cumella and Martin (2000) identified four key areas of difficulty, namely poor information on admission, limited staff training in the needs of people with a learning disability, risk to other patients (actual or perceived) and difficulties in obtaining consent that at times made staff wary of undertaking interventions. Nursing staff in acute general hospitals highlight their lack of preparation to work with people with a learning disability during their pre and post qualification education. The nurses are clear that further education and opportunities to develop skills are required and emphasise the need for skills in communication, legal and ethical issues (particularly informed consent and restraint), working with families, working with people who present challenging behaviour and the resources available to support people with a learning disability (Band, 1998; Barr, 2004a).

Conclusions

- Action to respond to the additional physical health needs of people with a learning disability is often not clearly stated in health policy documents.
- Lack of policy guidance and clear statements about the rights of people with a learning disability and service responsibilities exists in relation to the role of primary care and acute general hospitals services in responding to the health needs of people with a learning disability.
- Gains for people with a learning disability made in health screening and heath promotion projects may be short term due to the lack of recurrent funding to support the continuation of such initiatives.
- Limited collaborative working arrangements exist on an on-going basis between primary care, acute hospitals and specialist learning disability services.
- There is need for investment in training and education of staffing mainstream health services to increase their capacity to work effectively with people with a learning disability
- A more co-ordinated programme of research on the physical health needs of people with a learning disability and their access to / use of health service would provide a robust platform from which further develop primary care, acute general hospital and specialist learning disability services.

Conclusion

This chapter has sought to provide an analysis of the research evidence in relation to the physical status of people with a learning disability and the responses of health services to this. It is clear that people with a learning disability continue to have a high level of unmet physical health need and that while some limited progress has been made yet more needs to be done. Experience elsewhere in the United Kingdom has shown that efforts to improve the physical health of people with a learning disability should now focus on:

- Addressing the issues associated with health for all, and responding directly to the inequalities and discrimination against people with a learning disability in relation to their equity of access to healthcare.
- Developing increased capacity within primary care and acute hospital services
- Actively involving people with a learning disability, their families and carers
- Reshaping the contribution of specialist learning disability services to support the achievement of equity of access to healthcare, whilst still having the capacity to respond to the needs of people who can not have their needs met within mainstream services at present (Giraud–Saunders et al., 2003).

References

Band, R. (1998) *The NHS - Health for all? People with learning disabilities and healthcare.* London. Royal Society for Mentally Handicapped Children and Adults.

Barr, M., Kane, M., Keenan, K. & Cullen, J. (2003) A survey of dental services provided to people with learning disabilities in the Northern Health and Social Services Board area. *Tizard Learning Disability Review*, 8, 2, 4-13.

Barr, O., Gilgunn, J., Kane, T., & Moore, G. (1999) Health screening for people with learning disabilities by a community learning disability service in Northern Ireland. *Journal of Advanced Nursing* 29 (6): 1482-91.

Barr, O. (2004a – in preparation) *Promoting Access*: The experience of children and adults with learning disabilities and their families / carers who had contact with acute general hospitals in the WHSSB Area and the views of the nurses in these hospitals. A reported prepared for the WHSSB.

Barr, O. (2004b – in preparation) *The working practices of community nurses for people with learning disabilities and the people who use their services: Changes in Northern Ireland between 1992 and 2003.* A report prepared for the NICNLDPDF

Baxter, H. & Kerr, M. (2002) Barriers to health care services and the role of the physician. In Prasher, V.P. & Janicki, M. (eds.) *Physical health of adults with intellectual disabilities.* London, Blackwell Publishing / IASSID.

Beange, H (2002) Epidemiological issues. In Prasher, V.P. & Janicki, M. (eds.) *Physical health of adults with intellectual disabilities.* London, Blackwell Publishing / IASSID.

Beange H, Lennox N, and Parmenter T (1999) Health targets for people with an intellectual disability. *Journal of Intellectual and Developmental Disability* 24, 4, 283-298

Bond, L., Kerr, M., Dunstan, F. & Thapar, A. (1997). Attitudes of general practitioners towards health care for people with intellectual disability and the factors underlying these attitudes. *Journal of Intellectual Disability Research*, 41, 391-400.

Cassidy, G., Martin, D.M., Martin G.H.B. & Roy, A. (2002) Health checks for people with learning disabilities: community learning disability teams working with general practitioners and primary care teams. *Journal of Learning Disabilities*, 6(2)123-136.

Cooke, L. B. (1997) Cancer and learning disability. *Journal of Intellectual Disability Research*, 41(4) 312-316

Cumella, S. & Martin, D. (2000) *Secondary Healthcare for People with a Learning Disability. A report completed for the Department of Health.* (available at www.fons.org/networks/nnldn/a2a)

Department of Health (1995) *Health of the Nation. A strategy for people with learning disabilities*, Department of Health, London.

Department of Health, Social Services and Public Safety (2002) *Investing in Health*, Department of Health, Social Services and Public Safety, Belfast.

Department of Health, Social Services and Public Safety (2002) *A Fair Chance: Report on a consultation exercise facilitated by LEAD-Northern Ireland Coalition on Learning disability*, Belfast: Department of Health, Social Services and Public Safety.

DHSS&PS (2004) *We have a dream.* Belfast: DHSS&PS

Duff, M., Hoghton, M., Scheepers, M., Cooper, M. & Baddeley, P. (2001). Helicobacter pylori: has the filler escaped from the institution? A possible cause of increased stomach cancer in a population with intellectual disability. *Journal of Intellectual Disability Research*, 45, 219-225.

Gill, F., Stenfert Kroese, B. & Rose, J. (2002) General Practitioners' attitudes to patients who have a learning disabilities. *Psychological Medicine*, 37:1445-1455.

Giraud-Saunders, A., Gregory, M., Poxton, R., Smith, C & Towell, D. (2003) *Valuing health for all: an action guide*. London. Kings Fund.

Finlay, L (2002) *Primary Concern: people with a learning disability.* WHSSB, Londonderry.

Fleming, P. (1999) Health promotion for individuals, families and communities. In Long, A (Ed.) *Interaction for practice in community nursing*. London, Macmillan.

Fox, D. & Wilson D. (1999) Parents' experiences of general; hospital admission for adults with learning disabilities. *Journal of Clinical Nursing*, 8:610-614.

Gordon, S.M., Donnie, R.A. & Snyder, J. (1998). Dental fear and anxiety as a barrier to accessing oral health care among patients with special care needs. *Special Care Dentist*, 18, 88-92.

Hart, S. (1999) 'Meaningful choices: consent to treatment in general health care settings for people with learning disabilities'. *Journal of Learning Disabilities,* 3 (1): 20-6.

Hatton, C., Elliot, J. & Emerson, E. (2003) *Key highlights of research evidence on the health of people with learning disabilities*. (available at http://www.doh.gov.uk/vpst/latestnews.htm#newdocs)

Hay, I. (2003) Community dental services for people with learning disabilities. *Tizard Learning Disability Review, 8, 2, 14-17.*

Health Evidence Bulletins Wales – Learning Disabilities. (2001) http:hebw.uwcm.ac.uk/learningdisabilities/index.htm

Hogg, J., Northfield, J. & Turnbull, J. (2000*) Cancer and people with learning disabilities*. British Institute of Learning Disabilities, Kidderminster.

Horwitz, S., Kerler, B.D., Owens, P. & Zigler, E. (2000) *The health status and needs of individuals with mental retardation*. Yale University, Connecticut.

Hunt, C., Wakefield, S., Hunt, G. (2001) Community Nurse Learning Disabilities – a case study of the use of an evidence-based health screening tool to identify and meet health needs of people with learning disabilities. *Journal of Learning Disabilities*, 5(1) 9-18

Jansen, D., Krol, B., Groothoof, J & Post, D. (2004) People with Intellectual disabilities and their health problems: a review of comparative studies. *Journal of Intellectual Disability Research*, 48(2)93-102.

Jones, R.G. & Kerr, M.P. (1997). A randomised control trial of an opportunistic health screening tool for people with intellectual disability. *Journal of Intellectual Disability Research*, 41, 409-415.

Kenny, C. (1999). The gentle touch. *Nursing Times*, 94, 24.

Kerr, M., Dunstan, F. & Thapar, A. (1996). Attitudes of general practitioners to people with a learning disability. *British Journal of General Practice*, 46, 92-94.

Leggett, P. (2001) *Footsteps to health*: multidisciplinary heath screening of adults with learning disabilities 1999-2001. Cullybackey, Maine Medical Centre.

Lennox, N. (2002) Health Promotion and disease prevention In Prasher, V.P. & Janicki, M. (eds.) *Physical health of adults with intellectual disabilities.* London, Blackwell Publishing / IASSID.

Martin, G. (2003) Annual health reviews for patients with severe learning disabilities: five years of a combined GP/ CLDN Clinic. *Journal of Learning Disabilities*. 7(1) 9-22.

Martin, D.M., Roy, A. & Wells, M.B. (1997). Health gain through health checks: improving access to primary health care for people with intellectual disability. *Journal of Intellectual Disability Research*, 41, 401-408.

Marshall, D., McConkey, R., & Moore, G. (2003) Obesity in people with intellectual disabilities: the impact of nurse-led health screening and health promotion activities. *Journal of Advanced Nursing*, 41(2)147-153.

Marshall, D., McConkey, R., & Moore, G. (2000) *Healthcheck 2000 Evaluation report*. Lisburn, Down Lisburn Trust.

Meehan, S., Moore, G. & Barr, O. (1995) Specialist services for people with learning disabilities. *Nursing Times*, 91(13)33-35.

McConkey, R., Moore, G., & Marshall, D. (2002) 'Changes in the attitudes of GP's to the health screening of people with learning disabilities' *Journal of Learning Disabilities*, 6(4): 373-384.

McConkey, R., Barr, O., Fleming, P. and Milligan, V. (2003). *Evaluation of Challenge 2000: Health Screening and Health Promotion Service provided by North & West Locality Consortium (Belfast) to people with learning disabilities. (Clifton Street Surgery, Belfast and EHSSB).*

Mencap (1997) *Living in fear.* Royal Society for Mentally Handicapped Children and Adults, London.

Mental Health Foundation (1996) *Building Expectations: Opportunities and services for people with a learning disability.* London: Mental Health Foundation.

National Health Service Executive (1998) *Signposts for success in commissioning and providing health services for people with learning disabilities.* Department of Health, London.

National Health Service Executive (1999a) *Once a day.* Department of Health, London.

National Health Service Executive (1999b) *The Healthy way: how to stay healthy a guide for people with learning disabilities.* Department of Health, London.

Niadoo, J. & Wills, J. (1994) *Health Promotion. Foundations for practice.* Bailliere Tindall, London.

Nunn, J.H. (1987) The dental health of mentally and physically handicapped children: a review of the literature. *Community Dental Health*, 4, 157-168.

O'Brien, G., Barnard, I., Pearson, J., Rippon, L. (2002) Physical Health and clinical phenotypes. In Prasher, V.P. & Janicki, M. (eds.) Physical health of adults with intellectual disabilities. London, Blackwell Publishing / IASSID.

Patja, K., Eero, P. Iivanainen, M. (2001) Cancer incidence among people with intellectual disabilities. *Journal of Intellectual Disability Research*, 45(4)300-307.

Seedhouse, D. (1986) *Health: Foundations for achievement.* Wiley, Bristol.

Singh, P. (1997) *Prescription for change.* Royal Society for Mentally Handicapped Children and Adults, London.

Slevin, E. & Sines, D. (1996) 'Attitudes of nurses in a general hospital towards people with learning disabilities: influence of contact of graduate and non-graduate status. A comparative study', *Journal of Advanced Nursing*, 24(6): 1116-1126.

Sowney, M. & Barr, O. (in press) Equity of Access to healthcare for people with learning disabilities: a concept analysis. *Journal of Learning Disabilities.*

Stein, K. (2000). Caring for people with learning disability: a survey of general practitioners' attitudes in Southampton and South-West Hampshire. *British Journal of Learning Disabilities*, 28, 9-15.

Stratford, B. & Gunn, P. (1996) *New approaches to Down syndrome.* London, Cassell.

Thornton, C. (1999). Effective health care for people with learning disabilities: a formal carers' perspective. *Journal of Psychiatric & Mental Health Nursing*, 6, 383-390.

Tiller, S., Wilson, K.I. & Gallagher, J.E. (2001) Oral health status and dental service use of adults with learning disabilities living in residential institutions and in the community. Community Dental Health, 18, 167-171.

Turner, S. & Moss, S. (1996). The health needs of adults with learning disabilities and the *Health of the Nation* strategy. *Journal of Intellectual Disability Research*, 40, 438-450.

Wake, E. (2003) Profound and multiple disability. In Gates, B. (ed.) *Learning disabilities: towards inclusion.* 4th ed. Edinburgh, Churchill Livingstone.

World Health Organisation (1946) *Official Records of the World Health Organization*, no. 2, (p.100). World Health Organisation, Geneva.

World Health Organisation (2001) *International Classification of Functioning, Disability and Health*. Geneva: World Health Organisation

Chapter 7:

Mental Health and Challenging Behaviours with People who have a Learning Disability

Overview

A major challenge for service commissioners and providers for people with a learning disability is the provision of effective, efficient and equitable services for people with a learning disability who present with challenging behaviours and/or mental health problems.

There is an extensive international research base going back 30 years or more indicating that challenging behaviour in people with a learning disability represents one of the greatest challenges to community care.

There is also a more recent, though expanding, evidence base indicating that mental health problems among the learning disabled population (as a dominant presenting feature, or co-morbidly with challenging behaviour) is also a major challenge.

People with challenging behaviours (CB) /mental health problems (MHP) can create many challenges for their family/carers and are recognised as those who are most frequently hospitalised for treatment and assessment. Although some research regarding this client group exists in Northern Ireland (NI) in general there is a paucity of research here in relation to this population.

This chapter has four main sections.

Section 1 details definitions and the prevalence of CB/MHPs.

Section 2 examines the impact they have for persons with a learning disability and for their carers.

Section 3 presents an outline of various service models and approaches.

Section 4 recommendations are made for service provision and future research based on the available evidence.

Section 1. Definitions

Challenging Behaviour

The phrase challenging behaviour (CB) was first used in the United States by members of TASH (The Association for People with Severe Handicaps) and was adapted in the UK by an 'Ordinary Life' working party which met at the King's Fund Centre. The intention was to focus on those who challenge services (Blunden and Allen, 1987). The idea behind use of this term is that it is meant to be less stigmatizing than labels such as aberrant or maladaptive behaviour. CB was seen as a term which enabled professionals and carers to work on a functional approach to such behaviours.

In addition these later terms can be misleading e.g. behaviours that we (the general population) may see as maladaptive can in some instances be adaptive for the person with a learning disability who displays them (Elder, 1996). A person who uses CB as a means of communication as they have limited other means to communicate is a good illustration of this. When labels are applied to people with a learning disability they are often used to make decisions about them e.g. when a label such as having 'aberrant behaviour' is applied to a person it can lead to them being excluded from community participation (Newman and Emerson 1991).

The term challenging behaviour is presently the most frequently utilised descriptor for people with a learning disability who present with behaviours that challenge services (Bell and Espie 2001; DoH 1993; Emerson 1995; Emerson 2001; Qureshi and Alborz 1992; Reed 1990; Russell 1997).

The most commonly cited definition of CB in the literature is:

> *'severely challenging behaviour refers to culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities'* (Emerson,1995, 44).

For operational purposes within this review the definition of CB put forward by Emerson will be used.

Cautions

It is beyond the scope of this review to present a protracted debate on the merits or problems with any definition of CB. However, a number of cautions do need to be stated and these are as follows:

1. It should be noted that the definition above by Emerson (1995) refers to 'severe' challenging behaviour. There is little merit in focusing on behaviours that are less than severe, as most people with a learning disability will display some degree of such behaviours. An exception to this should of course be with regard to any behaviours that are considered to be high risk in terms of escalation to severe CB.

2. Challenging behaviour is an umbrella term which encapsulates many meanings so there is a need to be specific about what is meant by the term. With regard to CB Naylor and Clifton (1993) state 'non-specific use of the term is accompanied by indiscriminate use... by front line care staff when referring to behavioural disorders across the spectrum'. In practice it is necessary to state specifically what behaviours are challenging, how and to what degree (see Slevin,1995).

3. Categories of challenging behaviours take on different constructs, forms and purposes, depending on convention, the individual involved and the environment in which the behaviour is displayed (Darbyshire and Whitaker 1990).

4. How others tolerate or accept the behaviour displayed is important. Lowe and Felce (1995) suggest challenging behaviour is socially constructed and it is 'open to subjective interpretation... [and in addition] the degree of challenge depends not only on the nature of the behaviour but also on the ability of others to tolerate, change or minimize the consequences of it.' For example staff working in hospital or residential settings can become accustomed to some challenging behaviours to such an extent that they do not see them as challenging at all. For example, Stanley (1997) describes a survey which initially identified pica, the eating of abnormal objects, by people with a learning disability to occur at a very low frequency. On further investigation it was found that many of the service providers in the survey did not see pica as challenging at all so they had not noted its occurrence.

Finally, while labels are strong social constructs there is no guarantee that using more socially accepted terminology (in this case challenging behaviour) will lead to people being viewed more positively; or indeed as Emerson (2001, 4) states 'it would... be mistaken to believe that minor changes in terminology are capable of bringing about major changes in practice'.

Mental Health Problems

Challenging behaviour is a relatively objective term that has observable phenomena. However, this is not so with respect to many mental illnesses, some of which rely on self-report by the client for accurate diagnosis. This creates difficulties in defining mental illness in clients who have problems with expressive communication and this often results in diagnosis being made via third-party reports (Moss 1995). To add to the difficulty many clients with a learning disability present mental health problems through displaying challenging behaviours (Dudley, et al. 1999; Ross and Oliver, 2002). Many mental illnesses are 'cloaked' or hidden by the person's learning disabilities and behaviours a concept referred to 'diagnostic overshadowing' (Menolascino, 1988; Reiss, et al. 1982)

The lack of an agreed term for 'psychiatric disorders' in people with a learning disability has created problems regarding acceptable terminology. Various terms have been used inter-changeably e.g. 'mental illness', 'mental disorder', 'psychiatric disorder', 'mental impairment', 'emotional distress' and 'emotional disorders'. Bouras (1999a) suggests using the term 'mental health problems' as it is more in keeping with a 'bio-psycho-social' approach to understanding the co-morbidity between the two conditions (Aman 2000; IASSID 2001).

The term 'dual diagnosis' has also been used throughout the literature to explain the co-existence of learning disabilities and mental health problems (Sturmey, 1995). However, this term can cause confusion as it has been employed within mainstream psychiatry to refer to people with a dual diagnosis of mental illness and an addictive disorder (Drake, et al. 1996), most commonly an addiction to alcohol.

Within this review the term 'mental health problems' (MHP) forwarded by Bouras (1999a) and 'dual diagnosis' to indicate a mental health problem co-existing with a learning disability will be used interchangeably.

Cautions

As with challenging behaviour a number of cautions with respect to people who have a dual diagnosis need to be stated, among there are:

1. Regarding the co-occurrence of mental health problems and challenging behaviours it should be kept in mind that a proportion of people showing severe challenging behaviours will have a mental health problem, but not all will. Conversely, a proportion of people with mental health problems will not show challenging behaviours. It is not always clear whether these sub-grouping are distinguished in past studies. In addition confusion often exists between challenging behaviours and mental health problems (Emerson, et al. 1999a; Moss, et al. 1998).

2. The under-reporting of mental health problems in people with a learning disability for reasons such as:

- Diagnostic overshadowing' (Reiss, 1982)
- Atypical symptomatology (i.e. a mental health problem being displayed through screaming, stereotypy and spontaneous crying (Reiss & Rojahn, 1993, Meins, 1995, Moss et al., 2000a)
- Cognitive and communication difficulties that are frequently associated with this population (WHO, 1996; Moss 1999a)
- Difficulty in using third party informants, particularly due to reliability issues (Moss, et al. 1996a; Moss, et al. 1996b; Prosser, et al. 1998).

3. Failure to recognise mental health problems in people with a learning disability due to a lack of specialist knowledge and training amongst front-line staff has been reported (TOPSS, 1999; Quigley, et al. 2001) e.g. community learning disability nurses (Gilbert, et al. 1998), social workers (CCETSW, 1996) and GP's (Bernard & Bates, 1994; Rodgers, 1994; Kerr et al., 1996; Singh, 1997; Day, 2000).

Prevalence - Challenging behaviour

As might be expected from the above discussion on defining challenging behaviours in people who have a learning disability, if there is lack of clarity in defining a concept then determining the prevalence of that concept will be extremely difficult. The difficulty with describing the prevalence of CB in people who have a learning disability has led to estimates being made which can only be considered as rough guidance. Zarkowska and Clements (1988) suggest that 60% of people with a learning disability display some type of challenging behaviour. However, only 20 people per 100,000 (less than half a per cent) present severe challenging behaviours (Mansell Report, DoH, 1993). The Mental Health Foundation (MHF 1996) suggests that 10% of people who are registered with a learning disability in Great Britain exhibit CB. As can be seen, how the CB is defined can have dramatic effects on its prevalence, in the former 'some type' of CB and in the latter 'severe' CB.

International prevalence

It may seem that looking at specific behaviours could lessen problems with identification of prevalence. Emerson (1992) undertook an extensive overview of the epidemiology of self-injurious behaviour, which is one type of challenging behaviour. He found that the prevalence rate for just one type of challenging behaviour, 'self-injury' has a large variance - 1.1% for people living at Home to as high as 77.6% in a Swedish hospital, with various prevalence figures being cited between these two extremes. Such extreme variations appear to depend on contextual setting and country of origin.

In a district of Finland Salovita (2002) found that among 261 people with a learning disability in adult residences 70% exhibited CB considered to be of a severe nature. It should be noted this was in staffed community residences and a large institution, which explains this high figure.

A US survey of over 91,000 persons served by the California Department of Developmental Disabilities reported that 6.3 persons per 10,000 of the general population or 14% of those with learning disabilities displayed CB (Borthwick-Duffy, 1994).

British studies

In the UK Kiernan and Moss (1990) found the prevalence of challenging behaviours in a hospital population to be 40%. Qureshi and Alborz (1992) estimated the prevalence of CB in a hospital to be 30%. Prevalence figures for challenging behaviours have been found in a national survey of 17% of all day school pupils with severe learning disabilities in England and Wales to be 8.2% (in n=2,000 pupils) for what this study classified as 'most difficult behaviours' and 14% (in n=3,400 pupils) in those pupils who displayed 'less difficult' behaviour (Kiernan and Kiernan, 1994). In a review of the literature on aggressive behaviour Allen (2000) found that between 2-20% of people with a learning disability displayed aggressive behaviour (the rate varying due to sample procedures and type of behaviour).

Quershi (1994) and her colleagues screened a sample of over 4,200 people in seven administrative districts in the North-West of England. Further studies were then undertaken by Emerson (2001) using similar methods in the same areas. These concluded that for every 10,000 of the general population there are 2.4 people on average who had a learning disability and serious challenging behaviours. This equates to an estimated rate of 1 in 13 (7.3%) persons with a learning disability also having serious challenging behaviours. Similar findings have been reported for the most severe types of CB (Mansell Report DoH, 1993; Joyce et al, 2001). However, this latter study also reported that among 448 individuals with a learning disability identified from within a general community of 670,000, as many as 19% display some degree of CB (Joyce, et al. 2001).

Irish estimates

A number of unpublished studies have been undertaken of challenging behaviours found in clients using learning disabilities services in the Republic of Ireland. The estimates range from 14% of clients in a Southern Health Board region (Connelly, et al, 1995) through 29% in the Galway area (Walsh et al, 1995) and 37% in Dublin (Mulrooney, et al, 1997). A survey in a large Cork service reported 50% of people with mild disabilities and 75% of those with profound learning disabilities had challenging behaviours (Desmond, et al, 2000).[1]

This variation arises from differences in samples used in the different studies as well as definitions of challenging behaviours. However if a median percentage across these studies of 30% is used, this would suggest that 22 people per 10,000 of those with a learning disability have challenging behaviours.

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[1] All these studies were cited in the Report by Eastern Regional Health Authority (2002).

Northern Ireland

In Northern Ireland there is little knowledge of the prevalence of challenging behaviour in the overall learning disabled population. However, research has been undertaken that has identified the number of people with CB on the caseloads of some professionals, or among those admitted to hospital.

In a survey conducted by Parahoo and Barr (1996) in NI the third most frequently reported role of community nurses for people with a learning disability (CNLD) was behavioural management. Previous studies support this (Jenkins and Johnson 1991; Mackay 1989; Parahoo and Barr 1994). Slevin (1998) in a survey of the total population of CNLD in NI found that among the nurses combined caseloads of 1,985 clients, 550 (28%) were reported to have challenging behaviours. The number of children was 642 and 206 (32%) had CB; the total number of adults was 1343 and 344 (26%) had CB.

In a survey of people admitted to Longstone hospital in Armagh over an 18-month period 57 people were admitted and 40 (70%) were reported to have CB (Slevin, et al. 2002), even though this was not always the main reason for admission. In the same survey a census was undertaken of all the people in the hospital on a given day (time 1) and this was repeated 9-months later (time 2), it was found that at:

> Time 1, 130 people were in hospital, 39 (30%) had CB
>
> Time 2, 135 people were in hospital, 37 (27%) had CB.

Therefore, within this hospital population at any given time around 28% of people will have CB and as many as 70% of new admissions for treatment and assessment may have CB.

Mc Conkey et al. (2002) examined 154 people with a learning disability admitted into a specialist hospital in Northern Ireland over a two-year period. As found with previous hospital studies the most common reason cited for admission was that of a wide range of overt challenging behaviours (69%). Further examination of these reasons for admission also found that aggression was a core event that led to the admission 40.2% of this population (Taggart, 2003).

Conclusions

The variations in the reported prevalence of challenging behaviour is confusing to say the least, but some conclusions can be drawn overall:

- CB has a higher prevalence in the learning disabled population than in others
- Specialist services such as hospitals for people with a learning disability, or people on the case loads of specialist learning disability teams may have as many as 25-70% of clients having CB
- While very serious CB may have a low prevalence figure most research indicates that overall around 10-15% of people with a learning disability present carers and services with major challenges (Emerson, et al. 2000).

Mental health problems

Obtaining agreed prevalence figures for mental health problems in people with a learning disability is as difficult, if not more so, than it is for CB. Historically there has been some dispute about whether persons with a learning disability can experience the same range of mental health problems as the non-disabled population. However, with recent advancements in diagnosis such arguments have diminished (Prosser, et al. 1998; RCP, 2001). Bouras (2003) state that people with a learning disability can experience the same range of mental health problems in virtually all categories of 'psychiatric disorders', and more importantly all of which are more prevalent in this population than in the general population (Collacott, et al. 1992; Cooper and Collacott 1993; Deb 2001b). Nevertheless, the under-reporting of dual diagnosis in this population continues (Day 1994; Patel, Goldberg et al. 1993).

UK and International Prevalence

Just as with CB there is a wide variation in the prevalence rates of people who have a dual diagnosis of learning disabilities and mental health problems (MHPs). The prevalence of MHPs in community based populations of people with a learning disability tends to be in the region of 10% (Borthwick-Duffy & Eyman,1990) to 20% (Taylor, Hatton et al. 2004), although prevalence figures approaching 50% have been reported (Cooper and Bailey 2001).

As might be expected much higher rates of MHPs have been reported in people with a learning disability within hospital settings i.e. Trower et al. (1998) reported a 76% prevalence rate and Taggart et al. (2003) reported a 65% prevalence rate within a hospital setting. The latter of these, Taggart et al, report this figure for a hospital for people with a learning disability in Northern Ireland.

Such diversity of prevalence rates can result from:

- The terminology employed,
- The type of psychiatric classification systems employed (i.e. ICD or DSM),
- The population studied (i.e. hospital, community referred or community representative sample),
- The level and severity of learning disability,
- And whether challenging behaviour, and autism, is included in the prevalence rates (Sturmey, 1999).

Northern Ireland

Two studies have recently been undertaken within Northern Ireland that have examined hospital admissions and prevalence rates for people with a learning disability. McConkey et al. (2002) reported that two-thirds (66%) of the 154 people admitted had an underlying psychiatric disorder using the recently developed DC-LD (Royal College of Psychiatrists, 2001) with depression (27.9%) and psychotic disorders (21.4%) being the two main mental health problems identified. These results reflect similar findings as reported in previous studies on people with a learning disability in hospitals (Morgan, et al. 2000; Seager, et al. 2000; Xenitidis, et al. 2004; Xenitidis, Henry et al. 1999) and community in-patient studies in England and Wales (Alexander, et al. 2001).

However, in the second study in NI Slevin et al. (2002) reported hospital prevalence rates of mental health problems to be lower (33.3%) than those cited by the other in-patient studies cited above. This could have been due to the classification system used in this study (i.e. ICD – 10), whereas the McConkey et al. Research employed the DC-LD in conjunction with the ICD-10. It could be the case that hospital admissions have a different focus in each hospital, or differences in catchment area i.e. the Slevin et al (2002) hospital serves a more rural area than the McConkey et al one which has admissions from a large city (Belfast) as well as rural areas.

No studies were found for this review which have reported the community prevalence rates of mental health problems in this population within Northern Ireland.

Summary

Advances have taken place in the diagnosis of dual diagnosis. In an attempt to provide a more accurate diagnosis of mental health problems in people with a learning disability, modifications have been made to the ICD-10 classification system (i.e. 'ICD-10 Guide for Mental Retardation' (WHO, 1996). More recently, the Penrose Society and The Royal College of Psychiatrists (2001) have developed the 'DC-LD: Diagnostic Criteria for Psychiatric Disorders for use with adults with Learning Disabilities/Mental Retardation'. This new classification system can be used with adults with moderate to profound learning disabilities (a group who are very difficult to diagnose) in addition to being used with individuals who have a mild learning disability in conjunction with the ICD-10 manuals, thereby providing better recognition of whether a mental health problem exists across this population.

Other advances in diagnosis have included the development of the 'The Psychiatric Assessment Schedule for Adults with Development Disability' (PAS-ADD). This has been found to be a reliable and valid method for psychiatric interviewing of people with a learning disability (Moss, et al. 1993).

In 1993 the Mansell Report stated with reference to mental health problems in those who have learning disabilities that 'between 25 and 50% of adults have additional mental health needs' (Mansell Report DoH, 1993, 4). This figure is substantiated by IASSID have recently reported to the WHO that:

> *'The rates of mental disorders (including behaviour disorders) are high, with a lifetime prevalence of nearly 50% in people with severe or profound intellectual disabilities, and about 20% to 25% in people with milder intellectual disabilities' (2001, p. 11).*

Conclusions

- It seems reasonable to assert that between 20-50% of people with a learning disability who contact various service agencies are liable to have a mental health problem.
- A variety of mental health problems are found in this population.
- Further research and development is required to reliably assess mental health problems in people with more severe leaning disabilities.

Section 2: The impact of challenging behaviour and mental health problems

It is now recognized that CB can occur as a result of behavioural leaning principles without any underlying mental health problem i.e. the behaviour is learnt and maintained by operant reinforcement. CB may also occur as a manifestation of a mental health problem, or CB may result from a person using previously learned behaviours to counter or deal with the negative affects of a mental health problem (Dudley, et al 1999, Emerson, 2001). The impact of CB or MHPs are usually related to the behaviours expressed by the person. For the purposes of this review the impacts are considered for both CB and MHPs within this section.

The impacts of these two conditions will be considered from two aspects, the impacts on the person and the impact on other people involved with the person, such as carers.

Impact on the person

An array of negative impacts has been reported for people who display CB; some of these are as follows.

Self injury

A person him or her self is adversely affected by the challenging behaviours they may display. The most serious physical effect on the person may be injury due to self-injurious behaviour (SIB) (Murphy and Wilson 1985) and SIB is one of the most distressing problems for carers to cope with (Oliver and Head 1993; Qureshi 1993).

Sleep disturbance

Piazza et al. (1997) suggest that as many as 88% of children with challenging behaviours experience chronic sleep disturbance. Quine (1991) suggests sleep disturbance in itself is a challenging behaviour and this seems a reasonable proposition. Whether it is accepted that sleep disturbance is a CB or not there seems little doubt that there is a relationship between daytime CB and sleep disturbance at night in people with a learning disability in that sleep disturbance tends to exacerbate daytime CB (Brylewski and Wiggs 1999; Remington 1993; Wiggs and Store 2001; Wiggs and Stores 1996).

Specific mental health problems

People with a learning disability may suffer from any of the full range of affective and psychotic disorders. In addition a factor which is often overlooked is that a significant number of this client group have expressive suicidal tendencies which may extend to suicidal behaviour (Rourke, et al. 1989). While atypical symptoms of mental illness are usually expressed via CBs and research has focused on this (Jenkins, et al. 1998) it should be kept in mind that many people, particularly those with less severe learning disabilities, do show similar typical signs of psychotic disorders (schizophrenia, manic episodes or bipolar disorders), or affective disorders (depression, anxiety states, phobias etc.) as do the general population (Dudley et al. 1999).

Adversities to social life

The presence of learning disability can lead to many social disadvantages due to negative attitudes held towards this client group (Fitzsimmons and Barr 1997; Slevin and Sines 1996). But the stigma, which leads to people with a learning disability being segregated in many areas of life, is exaggerated when they have additional challenging behaviours. A person who has CB is more likely to be socially rejected and isolated not only because of the behaviour they display, but also due to the barriers to their social interaction skills and development that challenging behaviours create (Johnson, 1987). Communication difficulties are often associated with challenging behaviours in people with a learning disability which further hinders social integration (Chamberlain, et al. 1993; Vig and Jedrysek 1995; Kevan 2003).

Health/social service dependence

Caring services dependence is an effect which touches the lives of people with a learning disability and challenging behaviours. As Moss, et al. 1997) state "People with challenging behaviour represent one of the largest groups who are referred to psychiatric and psychology services."

Challenging behaviour is probably the single most frequent reason for people being admitted to hospital or residential care, whether this is for respite, treatment or assessment. So admission, and or re-admission, to hospital or residential placement is another adverse effect on clients that challenging behaviour can lead to (Blacher 1994; Emerson 1999a). People with CB are also frequently the last people to move out of institutional care (Allen and Lowe 1995).

Medication use

The primary mode of treatment in the management of mental health problems, and also challenging behaviours, in those with a learning disability continues to be psychopharmacology (Aman 2000; Emerson's, Robertson et al. 2000). Findings that Taggart (2003) also reported for 154 people admitted into a specialist hospital in Northern Ireland.

However, Duggan and Brylewski (1999) in a review of the literature relating to the efficacy of psychoactive medication in treating schizophrenia in people with a learning disability reported that 'there is no trial-based evidence for the effectiveness, or ineffectiveness, of any anti-psychotic medication for those with intellectual disability and schizophrenia' (p. 98). Overall, there is strong empirical evidence to indicate that:

The prescribing of more than one psycho-active drug is quite common (i.e. polypharmacy) (Branford 1994; Fleming, et al. 1996),

The use of psycho-active medication has been a long-term management strategy (Wressel, et al. 1990). Where psycho-active drugs have been used long-term, they were found to be rarely reviewed and individuals have been maintained on maximum dosages (Wressel et al., 1990; Fleming et al, 1996),

The employment of psycho-active drug regimes have been employed in isolation from alternative strategies (i.e. behavioural, educational and environmental) to manage both challenging behaviours and psychiatric problems (Flemming et 1996, Ahmed et al., 2000, Taggart, 2003),

There is a persistent problem of over prescribing psycho-active medication for this population (Reiss & Aman, 1998)

Higher levels of psychoactive medication have been found to be used in the learning disability hospitals (between 50% - 70%) compared to lower rates of these drugs being prescribed in the community (between 36% - 48%) (Branford, 1994, Fleming et al., 1996, Emerson et al., 2000).

In a study by Qureshi many of the parents saw the benefits of medication but others felt '*they would rather put up with the behaviour problems than have there child reduced to what several described as a zombie state*" (Qureshi 1993, 108). Remington (1993) cites similar negative views of medication use expressed by parents. As Slevin (1996) suggests these drugs 'act indiscriminately damaging many organs in the body' and according to Wolfensberger (1994) they may prematurely end lives.

The use of medication per se cannot always be viewed as negative. Godin (1996) suggests 'physicalism' - the development of physical treatments for people with mental health problems such as major tranquillisers have influenced the development of psychiatric community nursing. There is no doubt that these drugs have played a vital part in mental health and learning disabilities care transferring from hospital to community. Most would agree that if such drugs had not been developed many people who live in the community today would still be living in hospitals. It is not the ***use*** of medications which can create difficulties for people with a learning disability and challenging behaviours, but rather the ***misuse***.

Impact on carers and other family members

Caring family members

The effects of challenging behaviour on clients that are discussed above cannot be considered in isolation as they permeate the total family unit. For example when children suffer sleep disturbance parents also are affected (Wiggs and Stores,1996; Wiggs & Stores, 2001).

Qureshi (1993) in her study found that parents of children with challenging behaviours had social and leisure restraints, high malaise levels and that there was a high social cost for the parents of these children. Ill health in parents and injury to family members by the person who has the challenging behaviour has also been reported (Kieman and Alborz 1995a; Kiernan and Alborz 1995b).

It does therefore seem that parents of children with a learning disability and challenging behaviours are exposed to high levels of personal stress and social isolation (Stalker, 1988). This is a cause of concern as social support can have a buffering effect on family stress in caregiving which contributes to family well-being (Fink 1995), and vice versa, lack of social support can contribute to family adversity.

Gender inequality in the burden of care

Evidence suggests that the ideology of community care focuses on women as the main carers (Seltzer, et al. 1995; Smith, et al. 1995). In a study in a H&SSB area in Northern Ireland it was found that there were 217 families caring for people with severe learning disabilities where the mother was the sole carer, in contrast only 30 fathers held this role. In other words the mother was seven times more likely to be the sole carer than the father (McDonald and Mackay, 1997). Reviewing literature in this area Willoughby and Glidden (1995) state:

> '*fathers of the children with disabilities participated significantly less in caring for their children than did fathers of children without disabilities*'.

CB can add to the stress on the parent. Quine and Pahl (1985) investigated stress in families of children with severe learning disabilities in South East England and found the most significant stress factor to effect families was behavioural problems.

Effects on siblings

Referring to disability in general McHaffie and Atkinson (1993) state:

> *'The impact of care is not confined to the key carer. Rather it ripples through the social network with its potential for harm, frustration and conflict.*

Coleby (1995) utilised valid and reliable scales to compare anxiety levels, social restrictions and contact with friends between a group of siblings of a severely disabled brother and a matched comparison group of siblings selected from community child health records. Findings were that the siblings of the severely learning disabled children were shown to have less contact with friends and increased levels of anxiety compared to the comparison group. This supports the argument that challenging behaviour in children with a learning disability can also lead to adverse effects for a sibling within the family.

Respite provision

The provision of respite care can be a particular problem when the person with a learning disability has additional challenging behaviours. It is frequently reported in the literature that people with challenging behaviours are either excluded from respite due to their behaviour, or that services do not have adequate facilities or staff to meet this client groups respite needs (Duff, 1992).

In a survey undertaken in Northern Ireland to investigate the provision of respite care 101 respite services/facilities were identified. Over half the practitioners interviewed for the survey (n=42) believed significant gaps existed in respite care for children with challenging behaviours, and there was still a reliance on hospital use for respite for clients with CB (Sines, et al 1994). Poor respite provision leads to negative outcomes for all members in a caring family.

Relationships within caring families

It seems that the many stresses, anxieties and adverse effects on the health status of carers of people with a learning disability and challenging behaviours can lead to marital disharmony (Seideman and Kleine 1995). Seideman and Kleine (1995) found marital stress related to the child was a major contributor to divorce in nine parents in a sample of 52 parents of children with developmental or learning disabilities interviewed. Gallagher (1995) suggests that parents may use the tactic of blaming each other for the child's difficulties in an attempt to repress the emotional hurt involved when a child in the family has a learning disability.

Conclusions

When all the above factors co-exist, people who have a learning disability and CB/MHPs are adversely affected in almost all areas of life. Their behaviour can hinder their education, work or day care placement, social and recreational life, and relationships with other people and emotional development. In fact these people are often cited by policy makers for the need to retain institutional establishments for people with a learning disability (Collins 1992; Mansell 1995). These adversities are not confined to the person him/her self but rather they pervade the total family and often permeate to the wider community.

Section 3: Service models and approaches

The European Association for Mental Health in Mental Retardation (MH-MR) (Deb et al., 2001b) has recently published guidelines on the assessment and diagnosis of mental health problems in adults with a learning disability. These practice guidelines indicated that a systematic and comprehensive approach would be necessary to provide an accurate diagnosis. The guidelines indicated that a number of areas should be examined. These include family, personal, history, medical, psychiatric, medication and a history of presenting complaint.

Emerson et al (1998b) indicated that a wider framework is required for the provision of an accurate assessment, a clinical diagnosis and the development of 'socially valid efficacious interventions'. A dynamic interaction of biological, psychological, developmental and social factors may contribute to the development of a mental health problem in this population (Gardner & Sovner, 1994, Aman et al., 2000, IASSID, 2001).

Treatments, therapeutic interventions and management strategies

The two most widely used interventions for both CB and MHPs are medications and behavioural interventions (Allen, 2000). Alongside medication, behavioural interventions have also been reported to be very effective in not only treating challenging behaviours but also in treating specific mental health problems such as depression, anxiety and phobic disorders (Benson 1990).

Evidence suggests behavioral interventions involving an explicit functional analysis of behaviour are the most effective means of assessment and treatment for people with CB (Ager and O'May 2001). However, Emerson & Kiernan (1997a, b) and Emerson et al. (2000) have found that despite the advances in behavioural interventions, many people with challenging behaviours and also mental health problems are unlikely to receive effective behavioural support in the UK.

In terms of '*talk therapies*', there is growing empirical evidence of the effectiveness of using Cognitive-Behaviour Therapy (CBT) in successfully treating mental health problems in people with a learning disability (Stenfert Kroese, et al. 1997). Beail (1998, 2000) in England has shown that psychotherapy can also be successfully employed to treat this population particularly for those with a mild to moderate disability. Other authors have reported that people with a learning disability can effectively engage in therapeutic counselling regarding bereavement (Dowling, et al. 2003; Persaud and Persaud 2003; Reed 1990).

However CBT, psychotherapy and therapeutic counseling is rarely offered to people with a learning disability across the UK (Hassiotis 1999; Hollins and Dowling 2002; Mencap 1999). These findings have recently been echoed in Taggart's (2003) study that examined the community services offered to people acutely admitted into, and following discharge, from a specialist hospital in Northern Ireland.

Collins (1999) reported that mental health problems, and also challenging behaviours, in people with a learning disability rarely existed in isolation, and that such problems are almost invariably associated with the individual's psycho-social environment. An expert panel of psychiatrists and psychologists in the USA recently developed best practice guidelines regarding the 'treatment of psychiatric and behavioural problems' in this population (American Journal on Mental Retardation, May, 2000). These guidelines provided a bridge between the current scientific research on treatment efficacy and clinical practice.

In addition to indicating that medication was the first line of defence in the treatment of a psychiatric disorder, the panel identified seven 'psychosocial interventions that they recommended across a variety of circumstances. These circumstances included children, adolescents and adults; mild, moderate to sever/profound learning disabilities; from mild to persistent problem behaviours and for a wide variety of mental health problems. Out of these seven psychosocial interventions identified the panel uniformly agreed upon three psychosocial interventions that 'were the most highly recommended in almost every situation' (Aman et al., 2000, p. 171). These interventions are: applied behavioural analysis (ABA), managing the environment, individual and/or family education.

However, Taggart's (2003) study found that ABA, environmental modification and education were rarely offered to the people discharged from the specialist hospital within Northern Ireland.

Service Models

Specialist teams

Service provision for people with a dual diagnosis has traditionally been provided within the community learning disability teams supported by the specialist hospitals throughout most of the UK and wider. In order to meet the complex needs of those individuals that exhibit an array of challenging behaviours and/or mental health problems, 'community specialist teams ' have been established (Kings Fund, 1980, Bicknell, 1985, DoH 1993, Day, 1994).

There is strong empirical evidence of the effectiveness of these teams (Lowe, et al. 1996; Toogood, Bell et al. 1994a) and how they can diminish hospital admissions (Colond & Wieseler, 1995; Allen 1998). Several authors have cited that the core advantages of such teams relates to them being community-based, accessible and consisting of a multi-professional, multi-agency approach (Allen and Felce 1999; Bouras and Holt 2000). Despite such optimism, the availability, variation and effectiveness of specialist community teams has been found to be considerable (Roy & Cumella, 1993, Lowe et al., 1996, Allen & Felce, 1999). For many people with CB/MHPs, relatively few are likely to obtain access to such teams (Cumella & Chung, 1996, Qureshi, 1994, DoH, 1999a, Joyce et al., 2001). Findings that Mc Conkey et al. (2002) and Slevin et al. (2002) also reported regarding those people acutely admitted into two specialist hospitals in Northern Ireland.

[illegible]

Bouras et al. (2003) suggest that these teams continue to struggle to meet the needs of those with a mild learning disability: a cohort who are likely to have an underlying MHP and thus require a psychiatric assessment (Burns 2001). One of the major reasons cited for this difficulty centres upon such community teams lack of integration within mainstream psychiatric services: findings that Taggart (2003) also reported within Northern Ireland. Such a division has contrasted with the government's recommendations that learning disability teams should liaise with mainstream psychiatric services in order to effectively meet the needs of the learning disability population (Chaplin 2004; Bouras 2003; Royal College of Psychiatrists, 2003; DoH 2001; Darbyshire and Whitaker 1990; Fletcher, Beasley et al. 1999).

The National Service Framework for mental illness recommends, assertive community out reach, crisis intervention and intensive community support teams be used to support people who have severe and enduring mental illness. Intensive community support teams are also suggested as an effective support model for people with a learning disability who have MHPs. A significant number of people with mild learning disabilities have MHPs (Hassiotis, 1999 & 2001)

Intensive care management (ICM) is a model of service delivery that involves intensive client support aimed at enhancing social functioning and adaptation. Hassiotis (2001) found that for clients who have mild and borderline learning disabilities co-existing with psychosis ICM can reduce the number of hospital admissions and the duration of time spent in hospital for those who are admitted. Hassiotis also reported that clients in their study reported fewer unmet needs and higher levels of satisfaction than clients not receiving ICM. The study also provides evidence that ICM may be cost effective for this client group. Overall it is suggested that people with mild learning disabilities who have a psychotic illness may benefit more from ICM than clients with psychoses who have not got a learning disability.

Advantages of teams

Emerson (2001) reviewed the sizeable number of studies that were carried out in the 1990s into specialist teams. He noted the following:

- The teams were effective in providing behavioural support to clients in a variety of community setting with evident reduction in either their challenging behaviours and/or increased tolerance of community staff to the behaviours.
- Teams reduce the number of admissions/re-admissions to institutions and specialised units.
- Enhancements in the persons' quality of life and adaptive skills are reported along with higher carer satisfaction and improvements in the carers' coping with these behaviours.
- They are more cost-effective than institutional-based services.

Shortcomings of teams

However all teams are not uniformly successful. Allen and Felce (1999) identified certain factors that are likely to enhance the effectiveness of specialist teams.

- The team needs to have a broad skill base that enables them to intervene with the diversity of clients who will present with challenging behaviours. Teams members require specialist training for their task that combines expertise from both mental health and intellectual disabilities.
- They need to be able to provide support over a long-term and not just when a crisis arises and is apparently resolved. They need sufficient resources for this to happen.
- They need to use a clear conceptual model for their intervention that is shared by all team members and which can be readily communicated to others.
- The ability to support carers and staff in reactive behavioural management strategies.

- An efficient and clear management structure for referrals, allocation of cases, emergency contacts and named liaison staff for different services.
- The ability to deploy staff in services so that they can model and establish effective ways of working with people who present severe challenges.

Moreover, teams in themselves cannot provide the solution to people who have to be moved from their present residence because of the threat they pose to themselves or others. Some form of short-stay facility will be required.

Specialist treatment units

There have been moves in recent years towards the establishment of specialised treatment units for people who display challenging behaviours. In these units staff are trained in the use of a range of the interventions discussed above. Newman and Emerson (1991) undertook a postal survey of 19 specialised treatment units. The main findings were that the units functioned as assessment, intervention and containment units, and they provided staff training. The mean occupancy of the units was 12 places and a one-to-one full time staff member per service user was in place. They rarely provided an outreach service - except those units which have a higher staff client ratios.

Newman and Emerson (1991) summarise specialised units as follows. They provide environmental control, staff support and specialised resources, but they have the disadvantage of users modelling each other's problem behaviours, assessments don't take place in the natural setting and the quality of life is poorer than in community living.

In a study by Matthews (1995) which evaluated behavioural change in 19 clients selected from a population of 44, admitted to a special unit from 1989 to 1994, some impressive claims are made. From admission to discharge all 19 client's behavioural problems reduced in severity and most had stopped taking the behaviour modifying medication they had been on at admission. Improvement with this group of clients remained following discharge and over a year later none of the sample group had been readmitted to the unit.

Specialist treatment units have evolved since the early 1990s into various models. It seems they may have value in providing people who have challenging behaviours with intensive therapy from professionals, but staff in these units need to highly skilled otherwise they are liable to fail in their goals.

Specialist support services

Community teams and specialist units as unitary service models may have weaknesses. One way to improve on the weaknesses of each is to combine both within a service. Such a model is a specialist Intensive Support Service (ISS) that was evaluated in Wales by Allen (1999). The ISS consists of a small team of clinicians, a community support team and a 6-bed admission unit (Allen 1999b). While Allen acknowledge the ISS has problems as do other models it has reported success in:

- Creating positive change in clients CB and MHPs (Lowe et al. 1996)
- Enhanced skills and improved quality of life
- To have been associated with significant reductions in institutional admissions (Allen 1998b).
- A service such as this may be well placed to provide a seamless service for people with CB and MHPs.

Models based on inclusion (mental health & learning disabilities)

With fundamental changes in generic service provision for people with a learning disability per se, accompanied with the high prevalence rates, and current advancements regarding diagnosis and clinical interventions, new models of service provision are beginning to be developed in order to meet the heterogeneous needs of this population (Hassiotis et al., 2000 Cole, 2002, Mc Carthy & Boyd, 2002, Bouras et al., 2003).

Policy developments in the UK and internationally (Jacobson, et al. 2002b; Jacobson, et al. 2002a) have examined the possibility of working in partnerships with generic mental health services. The use of more contemporary models of service provision for this specific population has focused upon a combination of:

- Non-institutional community-based mental health services supported by learning disability teams (Bouras and Drummond 1992),
- Establishing specialist treatment units in the grounds of psychiatric and in general hospitals (Charlot, et al. 2002; Gustafsson 1997)
- And/or employing earmarked beds in a generic psychiatric ward of a mainstream psychiatric hospital (Day, 1994, Alexander et al., 2001, Bouras & Holt, 2001). (see Appendix 7)

There are a growing number of peer-reviewed papers pertaining to integrated schemes (Davidson, et al. 1999). These community-based service teams or models are claimed to be exemplars of recent 'good practices' or 'benchmarks' in addressing the needs of the dually diagnosed population. Early reports from these schemes appear promising, particularly for those persons with a mild to moderate learning disability.

An example of a joint psychiatric service in the UK is the Mental Health in Learning Disability Specialist Service' (MhiLD) developed in London (Bouras et al., 2003). This is a collaborative service between community mental health and learning disability services. This applied service model emphasises the need for specialist inter-disciplinary, community and readily accessible mental health provision for this population, therefore, ensuring co-ordinated services and effective liaison and integration with other agencies.

In a recent working paper, Bouras et al. (2003) provides a synopsis of the services provided for people with a learning disability and mental health problems within South London & Maudsley NHS Trust (population of approx. 650, 000). This model of a community-based mental health specialist service operates within the same service principles as other specialist mental health services and teams developed across the UK (i.e. child and adolescent mental health teams (CAMH), old age mental health teams, forensic mental health teams). This community-based team for people with a learning disability and mental health problems is based upon a collaborative service between learning disability and mental health service providers. The model of service provision emphasises a strong inter-disciplinary, community-based, accessible service that is based within a generic mental health service although it is strongly associated, integrated and supported by learning disability services. These specialist mental health teams have clear definitions of their specific roles and responsibilities. Bouras et al. (2003) highlights that this service offers prevention, assessment, therapeutic intervention, follow-up, consultation and also acute in-patient facilities with a diverse clinical team.

Disadvantages to integrated mental health/learning disability services

O'Brien (1990) reported that for a number of individuals who exhibited severe challenging behaviours as a result of enduring mental health problems, attempts to care for this population in mainstream mental health settings in some English health districts have been extremely difficult to manage. Subsequently, such difficulties have led to 'out of district' hospital placements being sought.

There have been a number of factors that have been forwarded to explain why mainstream psychiatric services have not been used to satisfactorily manage this population (Day 1994, Bouras et al., 2003, Xenitidis et al., 2004). These have included; the inappropriateness of the setting; a lack of staff knowledge and expertise; failure to integrate with their non-disabled counterparts (although it is more likely that mainstream psychiatric clients would fail to integrate with learning disabled people). In addition current therapeutic interventions employed within general mental health settings (i.e. counselling, psychoanalytic therapy and CBT) may not be posited correctly to each person's cognitive capacity.

Reiss (1994) highlighted that the lack of joint service development, has been a consequence of an historical separation between the traditional learning disability psychiatric services and the mainstream psychiatric services. This creation has lead to administrative issues in providing joint services, as both organisations have been opposed to, and non-committed to, the integration of learning disability and mainstream psychiatric services. Furthermore, as psychiatric provision in learning disabilities has been the 'Cinderella' specialty within psychiatry, funding issues have not been discussed and negotiated between the two service providers (Bouras et al., 1995, O'Dwyer, 2000).

The most significant of these problems is that learning disabled people may not have their special needs (due to their learning disabilities) met. This could create difficulties for people who present with challenging behaviour (not due to a mental illness) as it is not clear how the needs of this population would be met. A word of caution is required here and it is best illustrated by reference to the *Thomas S. v. Flaherty* 1988 class action law suit sited in Dudley et al. (1999). The case involved 940 people with a dual diagnosis in North Carolina. They were placed in state psychiatric hospitals and the case centred on them being treated for mental illness without due attention to their learning disabilities. The judge concluded that:

> *'the Thomas S class action members had constitutional rights that had possibly been denied, including: safety, protection from harm, treatment under safe conditions, freedom from undue restraint, and minimally adequate treatment or habilitation'* (Calhoun, Dudley et al. 1993).

Forensic (offending) behaviours

There is evidence that people with a learning disability do break the law from time to time, yet overall prevalence rate studies do not indicate that this population are any higher in offending compared to their non-disabled counterparts (Simpson & Hogg, 2001a).

Lindsay et al. (2001) reported that people with a learning disability may commit offences across the spectrum of criminal behaviours although there appears to be a higher rate of sexual offences (particularly against younger and male children), arson and violent crimes.

The significant risk factors that might lead this population to offend include: being young, male, having a borderline/mild learning disability, having a history of anti-social behaviours, using substances hazardously, having a mental health problem, being unemployed, living within family units that are dysfunctional with multiple losses and being raised in a socially deprived area (Winter et al., 1997, Murphy & Mason, 1999, Simpson & Hogg, 2001b).

Debate surrounds whether people with a learning disability should enter the mainstream criminal justice system including prisons compared to their non-learning disabled counterparts. Murphy & Fernando (1999) indicated that this population's needs may be better met within health and social services rather than through the criminal justice system. Despite such recommendations, a number of people with a learning disability continue to be questioned today in police stations, appear before magistrates and receive custodial sentences spending significant periods within prisons across the UK (Gujonsson et al., 1993, Lyall et al., 1995, Mason, 1997).

With regards to the assessment, treatment and management of this population this may be a complex process particularly given the specific offending behaviour that has led to police investigation and/or legal detention. This is accompanied with other co-morbid factors such as mental health problems, substance misuse disorders and the other factors identified above. Engaging with the criminal justice system is difficult for people with limited cognitive and communication skills. Further complexity remains in obtaining informed consent, and accurately assessing the person's capacity to consent, regarding both being interviewed and also taking part in various treatment packages (Clare & Murphy, 1998).

A comprehensive assessment of people with forensic needs should involve many different agencies (e.g. learning disability services, education, probation, housing, health) who should also be involved in treatment and long-term management of any client who presents with forensic or offending behaviours Assessment and treatment is likely to include detention within specialist hospitals and also penal institutions. Whatever the particular combination of interventions identified these will be likely to involve three core strategies: direct treatment with the person; preventative and management of further offending/alleged offending behaviour, and lifestyle changes (i.e. applied behaviour analysis, cognitive-behavioural therapy, individual/group education, medication, diversion out of the criminal justice system) (Clare & Murphy, 1998, Duggan & Taylor, 2000, Halstead et al., 2001). Community care should not overlook this group of clients and specialist forensic community support teams will be an essential element of any overall service that addresses the needs of all clients and their families.

There is a growing interest in this population, and some evidence of the effectiveness of multi-factorial intervention models in meeting the needs of clients with forensic problems, but there is a continuing need for further research into the factors that predispose, precipitate and maintain this learning disability population to offend.

Provision in Northern Ireland

In Northern Ireland, most of the expertise for managing the dually diagnosed population is located within specialist hospitals with an outreach service being provided by psychiatry. Taggart (2003) highlighted that many of the community residential facilities were inadequately resourced to provide specialist provision for these residents' needs. Moreover, Taggart (2003) also reported the lack of specialist and integrated service provision for this population throughout Northern Ireland.

In order to provide a more effective service for this dually diagnosed population within Northern Ireland, Taggart (2003) provided a number of recommendations for better service provision at the level of the individual; in community services for people with a learning disability and in specialist provision (see also Chapter 9). These recommendations have been supplemented with the most recent empirical evidence-based practices derived from the bio-psycho-social model (identified earlier).

Family support

Family support is essential if any care model is to succeed in supporting this client group in the community (Turnbull and Turnbull 1990). It is unlikely that there will ever be enough resources to provide the amount of intensive support people with CB/MHPs require (although lobbying for this is essential). Therefore, to achieve success education and support for caring families is essential. This is in keeping with current philosophy on 'shared caring' and 'person-centred care provision. In relation to challenging behaviours it has been stated that 'interventions which succeed in one place often fail to generalise when the person moves back to their own home' (Finley, et al. 1995). This might be considered a model of care that supports and empowers parents (Darbyshire and Morrison 1995).

How well the shared perspectives to care work in community settings with people who have CB has not yet been fully evaluated. It does however seem reasonable to suggest that if programmes of care to reduce challenging behaviours in clients in community settings are used without consistency in approach between community staff and carer, then such programmes are likely to be unsuccessful.

Signposts is an approach which involves providing parents with a package that includes books, video and workbooks (Hudson, et al. 2003). The package is underpinned by applied behavioural analysis principles. Parents are provided with one of three types of support: group support, telephone support and self-directed. Hudson et al (2003) report that use of the system led to a decrease in stress by parents, confidence in dealing with children's CB, and improvement in their children's behaviours. This and similar approaches are essential if care for people with CB/MHPs is to succeed.

Other approaches

It is beyond the scope of this review to provide detailed accounts of the wide variety of approaches that may have value to this client group, some such approaches are listed below although the evidence-base for their effectiveness is still evolving.

Music therapy

There have been quite a few published single-case studies that have demonstrated music therapy can reduce challenging behaviours in people who have a learning disability (Ritchie 1993; Walsh 1997).

Multi-sensory therapy (Snoezelen):

Although this is mainly a leisure and recreational facility, it may also have therapeutic value (Hulsegge and Verheul 1987). It has been successful in helping with CB (Bunsen 1992; Shapiro, et al. 1997; Slevin and McClelland, 1998)

Treatment and Education of Autistic and related Communication handicapped Children *(TEACCH)*:

This structured approach can be successful in maintaining community living for people with autism (Schopler, et al. 1982) and helpful with CB (Sines et al. 1996).

Complementary therapies

These may also have value (Sayre-Adams 1994). Aromatherapy: useful for other client groups (Brooker, et al. 1997; Cannard 1996) but limited research in learning disabilities.

Massage can induce relaxation (Hegarty and Gale 1996).

Corbett (1993) discusses how acupuncture and pressure massage to specific areas of the body can stimulate nerve pathways to the brain and possibly alter neurotransmitter adversities. If this information could be harnessed and used, for example, to actively induce relaxation in people who are hyperactive, aggressive or self-injure, then the cognitive limitations of such clients to benefit from directed relaxation therapy could be overcome. But there is limited evidence to support these treatments at present.

Conclusions

Service models have been conceptualised into those based in specialist units and those centred around specialised teams. In essence these two service responses serve complementary functions although as yet the evidence for the effectiveness of either is not wholly convincing.

A wide range of therapeutic approaches have been tried with varying degrees of success with medication remaining the primary method of at least containing problematic behaviours and behavioural treatments offering promise in managing them.

Further research and development is required to advance our knowledge base in creating more effective service responses for these groups of clients.

Section 4: Recommendations for service policy and practice

Emerging from this review and the models of service provision presented, there are a number of aspects that appear fundamental in the design of an effective service. These are summarised in this section and certain aspects are elaborated on in Chapter 9.

It is important that there is a clear and accepted definition of what is meant by challenging behaviour & mental health problem, and this should take into account the severity of any such conditions.

Staff require adequate training to allow them to identify mental health problems in clients and the concomitant relationship between CB and MHPs

Research to identify the prevalence of CB and MHP across various residential and community settings in NI would be useful to facilitate accurate assessment of need in this area

Service commissioners, providers and agencies need to take action to target the negative impacts of CB/MHP on the person with a learning disability and others; however such targeting needs to be proactive and preventative whenever possible rather than having to resort to reactive strategies. A full range of proactive and reactive interventions should be made available for this population with a strong emphasis on prevention and crisis management. This is inclusive of specialized programmes for developing emotional literacy, educational, social, recreational and occupational competencies. However, all CB/MHPs are unlikely to be prevented so there will need to be clear clinical guideline regarding reactive strategies when these are required.

Evidence suggests that there is a small cohort of people who develop severe CB which is intractable and life-long. This has two implications:

- This cohort of people may require a supported environment outside their normal home from time to time during their life; or alternatively intensive community support
- To prevent CBs becoming intractable and life-long 'early intervention' of an intensive nature will be required.

Any service model should be comprehensive and provide for the full spectrum of diagnostic groups.

There should be a strong interdisciplinary team approach and links with mainstream psychiatric services should be considered. However, labels and language carry messages so consideration should be given to the use of terms such as interdisciplinary and multidisciplinary on the grounds that terminology of this nature may exclude the client (and family) from the care planning process i.e. it is not in keeping with a modern philosophy of 'shared' and 'person-centred' care. A term such as a 'multi-caring' group would indicate wider membership than professionals only.

Equal access to a wide range of services within the individual's community should be a guiding principle. These include early screening; a comprehensive assessment, treatment and short and long-term support within the person's own home environment and/or alternative settings (i.e. day centre, school), the provision of respite care and the option of a placement within a community-based specialist treatment unit (see Chapter 9).

If hospitalisation is required then the in-patient facilities should provide a multi-modal package of specialized treatment programmes that acknowledges each of the different diagnostic groups.

A strong emphasis should be placed upon appropriately trained and experienced staff, and also the education of carers and individuals.

Funding must be made available for this sub-grouping of the learning disabled population (those with CB/MHPs) otherwise available evidence suggests community care will fail them and their families

Evidence supports the value of applied behavioural analysis (ABA) so there needs to be investigation into why this is not widely utilised across NI. To encourage the use of ABA it is suggested here that;

1) Clinical guidelines and protocols are established within services to ensure ABA is used

2) Staff are adequately trained in ABA technologies.

Contacts should be established with academic institutes so research can be conducted on the efficacy and cost-effectiveness of models utilised.

Conclusions

In summary no one model or approach will meet everyone's needs. The range of service models and approaches presented in this review should all be considered as options. The most important consideration is that whatever approach or model is used it should be guided by the following:

1. A person-centred approach should be fundamental and any approach or model used must meet the individual client (and family) needs
2. Approaches used to care for people with CB/MHPs need to be evidence-based
3. Staff who work with this client population must to be skilled in the interventions required to meet their needs, and in addition they will require professional support mechanisms to deal with the stress they may be exposed to.
4. Models of care used need to be flexible, varied and have applicability across specialist residential and community settings.

References

Ager, A. and F. O'May (2001). "Issues in the definition and implementation of 'best practice' for staff delivery of interventions for challenging behaviour." *Journal of Intellectual Disability Research*, **26**(3): 243-256.

Alexander, R. T., J. Piachaud, et al. (2001). "Two districts, two models: in-patient care in the psychiatry of learning disability." *The British Journal of Learning Disabilities*, **47**(2): 105-110.

Allen, C. (1998). "The care programme approach: the experiences and views of carers." *Mental Health Care*, **1**(5): 160-162.

Allen, D. (1998b). "Changes in admissions to a hospital for people with learning disabilities following the development of alterative community services." *Journal of Applied Research in Intellectual Disabilities*, **11**: 156-165.

Allen, D. (1999b). "Success and failure in community placements for people with learning disabilities and challenging behaviour: An analysis of key variables." *Journal of Mental Health, 8(3): 307-329.*

Allen, D. (2000). "Recent research on physical aggression in persons with intellectual disability: An overview." *Journal of Intellectual & Developmental Disability*, **25**(1): 41-57.

Allen, D. and D. Felce (1999). Service responses to challenging behaviour. In N. Bouras (ed.) *Psychiatric and Behavioural disorders in development disabilities and mental retardation*, Cambridge:, Cambridge University Press.: 279-294.

Allen, D. and K. Lowe (1995). "Providing intensive community support to people with learning disabilities and challenging behaviour: a preliminary analysis of outcomes and cost." *Journal of Intellectual Disability Research*, **39**(1): 67-82.

Aman, M. G., Alvarez, N, Benefield, W, Green, G, King, B H, Reiss, S, Rojahn, J & Szymanski, L (2000). "Special issue, Expert consensus guideline series Treatment of psychiatric and behavioural problems in mental retardation." *American Journal on Mental Retardation*, **105**.

Bell, D. M. and C. A. Espie (2001). "A preliminary investigation into staff satisfaction, and staff emotions and attitudes in a unit for men with learning disabilities and serious challenging behaviours." *British Journal of Learning Disabilities*, **30**(1): 19-27.

Benson, B. A. (1990). Behavioural treatment of depression. In A. Dosen and F. J. Menolascino (eds.) *Depression in mentally retarded children and adults*. Leiden, Netherlands Logon Publications: 309-329.

Bicknell, J. (1985): Educational programmes for general practitioners and clinical assistants in the mental handicap service. *Bulletin of the Royal College of Psychiatrists*, 8, 154-155.

Blacher, J. (1994). Placement and its consequences for families with children who have mental retardation. In J. Blacher (ed.) *When there is no place like home: options for children living apart from their natural families*. Baltimore, Paul H. Brooks: 213-243.

Blunden, R. and D. Allen, Eds. (1987). *Facing the Challenge: An Ordinary Life for People with Learning Difficulties and Challenging Behaviours*. London, Kings Fund Centre, Project Paper no 74.

Borthwick-Duffy, S. A. & Eyman, R. K. (1990). Who are the dually diagnosed? *American Journal on Mental Retardation*, 94, 586–595.

Borthwick-Duffy, S. A. (1994). Prevalence of destructive behaviours. In T. Thompson and D. B. Gray (eds.) *Destructive behaviour in developmental disabilities: Diagnosis and treatment*. Thousand Oaks, Sage, 3-23.

Bouras, N. (1999a). "Mental health and learning disabilities planning and service developments." *Tizard Learning Disability Review*, **4**(2): 3–5.

Bouras, N. and G. Holt (2000). The planning and provision of psychiatric services for people with mental retardation. In J. J. Lopez-Ibor and C. Andreason (ed.) *The New Oxford Textbook of Psychiatry*. Oxford, Oxford University Press.

Bouras, N. Holt, G. (2001): Community mental health services for adults with learning disabilities. In G. Thornicroft, & G. Szmukler, (eds.) *Community Psychiatry*.. Oxford: Oxford University Press. pp. 397-407

Bouras, N., Holt, G, et al. (2003). Services for people with learning disabilities and mental disorders. Working paper. London, Estia Centre.

Bouras, N., Holt, G. and Gravestock, S. (1995): Community care for people with learning disabilities: deficits and future plans. Psychiatric Bulletin, 19, 134-137.

Branford, D. (1994). "A study of the prescribing for people with learning disabilities living in the community and in the National Health Service care." *Journal of Intellectual Disability Research*, **38**(6): 577-586.

Brooker, D. J., Snape, M. et al. (1997). "Single case evaluation of the effects of aromatherapy and massage on disturbed behaviour in severe dementia." *British Journal of Clinical Psychology,* **36**(2): 287-296.

Brylewski, J. and Wiggs, L. (1999). "Sleep problems and daytime challenging behaviour in a community based sample of adults with intellectual disability." *Journal of Intellectual Disability Research,* **24**(6): 504-512.

Bunsen, D. (1992). A study in the use and implications of the Snoezelen resource at Liminton House School. In R. Hutchinson and J. Kewin (eds.) *Sensations and disability sensory environments for leisure, snoezelen, education and therapy*. Chesterfield, ROMPA UK Publications: 138-162.

Burns, T. (2001). Generic versus specialist mental health teams. In G. Thornicroft and G. Szmukler (eds.) *Textbook of Community Psychiatry*. Oxford, Oxford University Press: 231 – 241.

Calhoun, M., Dudley, J. et al. (1993). *The Thomas S. Case: Analysis of History, Policy, and Implementation , November 1992-February 1993. Thomas S. Longitudinal Study*. Charlotte, NC, University of North Carolina at Charlotte.

Cannard, G. (1996). "The effect of aromatherapy in promoting relaxation and stress reduction in a hospital." *Complementary Therapies in Nursing and Midwifery*, **2**(2): 38-40.

CCETSW (1996). *Assessing quality Rules and requirements for the DipSW*. London, Central Council for Educational Training in Social Work.

Chamberlain, L., Chung, M. C. et al. (1993). "Preliminary findings on communication and challenging behaviour in learning difficulty." *The British Journal of Developmental Disabilities*, **39**(2): 118-124.

Chaplin, R. (2004). "General psychiatric services for adults with intellectual disabilities and mental illness." *Journal of Intellectual Disability Research*, **48**(1): 1–10.

Charlot, L. R., S. Abend, et al. (2002). A short stay in patient unit for adults with developmental disabilities In J. W. Jacobson, J. A. Mulick and S. Holburn (eds.) *Contemporary dual diagnosis Mental health/mental retardation Service models: Volume 1 Residential and day services*. New York, NADD: 35-54.

Clare, I. & Murphy, G. (1998): Working with offenders or alleged offenders with intellectual disabilities. In E. Emerson, C. Hatton, J. Bromley & A. Caine (eds.) *Clinical psychology and people with intellectual disabilities*. Chichester: John Wiley & Sons. (pp. 154 - 176)

Cole, A. (2002): *Include us too: Developing and improving service to meet the mental health needs of people with learning disabilities. A workbook for commissioners and managers in* *mental health and learning disabilities services*. London: Institute of Health and Applied Social Policy.

Coleby, M. (1995). "The school-aged siblings of children with disabilities." *Developmental Medicine and Child Neurology*, **37**(5): 415-426.

Collacott, R. A., Cooper, S. A. et al. (1992). "Differential rates of psychiatric disorders in adults with Down's syndrome compared with other mentally handicapped adults." *British journal of psychiatry*, **161**: 671-774.

Collins, J. (1992). *When the eagles fly. A report on the resettlement of people with learning difficulties from long-stay institutions*. Wembley, Adept Press.

Collins, S. (1999). "Treatment and therapeutic interventions psychological approaches." *Tizard Learning Disability Review*, **4**(2): 20–27.

Colond, J. S. and Wieseler, N. A. (1995): Preventing restrictive community placements through community support services. *American Journal on Mental Retardation*, 100, 201-206.

Cooper, S. A. and N. M. Bailey (2001). "Psychiatric disorders amongst adults with learning disabilities prevalence and relationship to ability." *Irish Journal of Psychiatric Medicine*, **18**(2): 45-53.

Cooper, S. A. and Collacott, R. A. (1993). "Mania and Down's syndrome." *British Journal of Psychiatry*, **162**: 739-743.

Corbett, J. (1993). "Healing the mind through the body." *Mental Handicap*, **21**(3): 82-86.

Darbyshire, P. and Morrison, H. (1995). "Empowering parents of children with special needs." *Nursing Times*, **91**(32): 26-27.

Darbyshire, P. and Whitaker, S. (1990). "The final challenge." *Nursing Times*, **86**(2): 64-66.

Davidson, P. W., Morris, D. et al. (1999). Community services for people with developmental disabilities and psychiatric or severe behaviour disorders. In N. Bouras (ed.) *Psychiatric and Behavioural disorders in development disabilities and mental retardation.*. Cambridge, Cambridge University Press: 359-372.

Day, K. (1994). Psychiatric services in mental retardation generic or specialised provision? Mental Health in Mental Retardation recent advances and practices. N. Bouras. Cambridge, Cambridge University Press.

Day, K. (2000). Service provision and staff training an overview. In A. Dosen and K. Day (eds.) *Treating mental illness and behaviour disorders in children and adults with mental retardation*. American Psychiatric Press. Washington: 469-492

Deb, S. M., Holt, T G and Bouras, N (2001b). *Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability*. Brighton, MH-MR Pavillion.

Department of Health (1999a). *Once a Day*. London: NHS Executive.

DoH (1993). *Services for people with learning disabilities and challenging behaviour or mental health needs (Mansell Report)*. London, HMSO.

DoH (2001). *Valuing people: A Strategy for the 21st century*. London, HMSO.

Dowling, S., Hubert, J. et al. (2003). "Bereavement interventions for people with learning disabilities." *Bereavement Care*, **22**(2): 19–21.

Drake, R., F. C. Osher, et al. (1996). The dually diagnosed. In W. R. Breakey (ed.) *Integrated mental health services: Modern community psychiatry*. Oxford, Oxford University Press: 339-352.

Dudley, J. R., Ahlgrim-Delzell, L. et al. (1999). "Diverse diagnostic and behavioural patterns amongst people with dual diagnosis." *Journal of Intellectual Disability Research*, **43**(2): 70-79.

Duff, G. (1992). "Respite choice." *Nursing Times*, **88**(33): 65-66.

Duggan, L. and Taylor, J. (2000): Referrals to a new medium secure unit for men with borderline/mild learning disability. Report given at the Royal College of psychiatrist Learning Disability Section Annual Conference.

Duggan, L. and Brylewski, J. (1999). "Effectiveness of anti-psychotic medication in people with intellectual disability and schizophrenia a systematic review." *Journal of Intellectual Disability Research*, **43**(2): 94-104.

Eastern Regional Health Authority (2002) *Proposed Specialist Service for Clients with Intellectual Disabilities presenting with severe challenging behaviour and/or psychiatric illness.* Dublin: EHRA.

Elder, J. H. (1996). "Behavioral treatment of children with autism, mental retardation, and related disabilities: ethics and efficacy." *Journal of Child and Adolescent Psychiatric Nursing*, **9**(3): 28-36.

Emerson, E. (1992). "Self injurious behaviour: an overview in recent trends in epidemiological and behavioural research." *Mental Handicap Research*, **4**(1): 49-81.

Emerson, E. (1995). *Challenging behaviour: analysis and interventions in people with learning difficulties.* Cambridge, Cambridge University Press.

Emerson, E. (2001). *Challenging behaviour: analysis and interventions in people with learning difficulties (2nd. Edition)* . Cambridge, Cambridge University Press.

Emerson, E., Hatton, C., Bromley, J. and Caine, A. (1998b). *Clinical psychology and people with intellectual disabilities.* Chichester: John Wiley & Sons.

Emerson, E., Robertson, J. et al. (2000). "Treatment and Management of Challenging Behaviours in Residential Settings." *Journal of Applied Research in Intellectual Disabilities*, **13**(4): 197-215.

Emerson, E., Moss, S. et al. (1999a). The relationship between challenging behaviours and psychiatric disorders in people with severe developmental disabilities. In N. Bouras (ed.) *In Psychiatric and Behavioural disorders in development disabilities and mental retardation.* Cambridge, Cambridge University Press: 38–48.

Emerson's, E., Robertson, J. et al. (2000). " Treatment and management of challenging behaviours in residential settings." *Journal of Applied Research in Intellectual Disabilities*, **13**(197-215).

Fink, S. V. (1995). "The influence of family resources and family demands on the strains and well-being of caregiving families." *Nursing Research*, **44**(3): 139-146.

Finley, W. M., Duckett, S. et al. (1995). "Intensive community care assessment and intervention for challenging behaviour: a case study." *British Journal of Learning Disabilities*, **23**(1): 18-23.

Fitzsimmons, J. and Barr, O. (1997). "A review of the reported attitudes of health and social care professionals towards people with learning disabilities: implications for education and further research." *Journal of Learning Disabilities for Nursing Health and Social Care*, **1**(2): 57-64.

Fleming, I., Caine, A. et al. (1996). "Aspects of the use of psychoactive medication among people with intellectual disabilities who have been resettled from long-stay hospitals into dispersed housing." *Journal of Applied Research in Intellectual Disabilities*, **9**(3): 194-205.

Fletcher, R. J., Beasley, J.et al. (1999). Support service systems for people with dual diagnosis in the USA. In N. Bouras (ed.) *Psychiatric and Behavioural disorders in development disabilities and mental retardation.* Cambridge, Cambridge University Press: 373-390.

Foundation for People with Learning Disabilities (2002) *Count us in- report of an inquiry into the needs of young people with learning difficulties who have mental health needs.* London: Foundation for People with Learning Disabilities

Gallagher, L. N. S. (1995). "The impact of learning disabilities on families." *Journal of Child Neurology*, **1**: 112-113.

Gardner, W. I. and Sovner, R. (1994). *Self-injurious behaviours: A functional approach*. Willow St, PA: Vida Press.

Gilbert, T., Todd, M. et al. (1998). "People with learning disabilities who also have mental health problems practice issues and directions for learning disability nursing." *Journal of Advanced Nursing*, **27**: 1151-1157.

Godin, P. (1996). "The development of community psychiatric nursing: a professional project?" *Journal of Advanced Nursing*, **23**(5): 925-934.

Gudjonsson, G., Clare, I., Rutter, S. & Peasre, J. (1993): *Persons at risk during interviews in police custody: the identification of vulnerabilities*. The Royal Commission of Criminal Justice, Research Study No. 12. London: HMSO.

Halstead, S. M., Cahill, A. and Fernando, L. (2001): Discharges from a learning disability medium secure unit: what happens to them? *The British Journal of Forensic Practice*,

Hassiotis, A. (1999). "Psychodynamic psychotherapy in learning disability theory and practice revisited." *Journal of Learning disabilities for Nursing, Health and School Health Care*, **3**(2): 106–109.

Hassiotis, A. (2000): Editorial: Mental health services for people with learning disabilities. *British Medical Journal*, 321, 583-584.

Hassiotis, A. , Ukomunne,O.C, Byford S. et al (2001): Intellectual functioning and outcome of patients with severe psychotic illness randomised to intensive case management. Report form the UK700 trial. *British Journal of Psychiatry*, 178, 166-171.

Hegarty, J. R. and Gale, E. (1996). "Touch as a therapeutic medium for people with challenging behaviours." *British Journal of Learning Disabilities*, **24**(1): 26-32.

Hoefkens, A. and Allen, D. (1990). "Evaluation of a special behaviour unit for people with mental handicaps and challenging behaviours." *Journal of Mental Deficiency Research* **34**: 213-218.

Hollins, S. and Dowling, S. (2002). *Helping adults with learning disabilities to survive bereavement and move on*. IASSID European Conference, Dublin.

Hudson, A. M., Matthews, J. M. et al. (2003). "Evaluation of an intervention system for parents of children with intellectual disability and challenging behaviour." *Journal of Intellectual Disability Research*, **47**(4/5): 238-249.

Hulsegge, J. and Verheul, A. (1987). *Snoezelen: Another World*. Chesterfield, ROMPA UK Publications.

IASSID (2001). *Mental health and intellectual disabilities Addressing the mental health needs of people with intellectual disabilities*, Report by the Mental Health Special Interest Research Group of IASSID (International Association for the Scientific Study of Intellectual Disabilities) to the World Health Organisation.

Jacobson, J. W. (1982). "Problem behaviour and psychiatric impairment within a developmentally disabled population: 1. Behavior frequency." *Applied Research in Mental Retardation*, **3**: 121-129.

Jacobson, J. W., Mulick, J. A. et al. (2002a). *Contemporary dual diagnosis Mental health/mental retardation Service models Residential and day services*. New York, NADD Press.

Jacobson, J., S. Holburn, et al. (2002b). *Contemporary dual diagnosis Mental health/mental retardation Service models Volume 1 Partial and supportive services*. New York, NADD Press.

Jenkins, J. and B. Johnson (1991). Community Nursing Learning Disabilities Survey 1991. Penarth, Mental Handicap Nurses Association.

Jenkins, J., Rose, J. et al. (1998). "The checklist of challenging behaviour and its relationship with the psychopathology inventory for mentally retarded adults." *Journal of Intellectual Disability Research* **42**(**4**): 273-278.

Johnson, D. (1987). "Nonverbal learning disabilities." *Pediatric Annals*, **16**(2): 133-144.

Joyce, T., Ditchfield, H. et al. (2001). "Challenging behaviour in community services." *Journal of Intellectual Disability Research*, **45**(2): 130-138.

Kerr, M. Fraser, W. & Felce, D. (1996). Primary health care for people with a learning disability. *British Journal of Learning Disability*, 24, 2–8.

Kevan, F. (2003). "Challenging behaviour and communication difficulties." *British Journal of Learning Disabilities* **31**(2): 75-80.

Kiernan, C. and Alborz, A. (1995a). *A different life*. Manchester, Hester Adrian Research Unit.

Kiernan, C. and Alborz, A. (1995b). "Persistence and change in challenging and problem behaviours of young adults with intellectual disability living in the family home." *Journal of Applied Research in Intellectual Disabilities*, **9**(3): 181-193.

Kiernan, C. and Kiernan, D. (1994). "Challenging behaviour in schools for pupils with severe learning difficulties." *Mental Handicap Research*, **7**(3): 177-200.

Kiernan, C. and Moss, S. (1990). "Behaviour disorders and other characteristics of the population of a mental handicap hospital." *Mental Handicap Research*, **3**(1): 3-20.

Kings Fund Centre (1980): *An ordinary Life: comprehensive locally based residential services for mentally handicapped people.* London: King Edwards Hospital Fund.

Lowe, K. and Felce, D. (1995). "How do carers assess the severity of challenging behaviour? A total population study." *Journal of Intellectual Disability Research*, **39**(2): 117-127.

Lowe, K., Felce, D. et al. (1996). "Challenging behaviour: the effectiveness of community support teams." *Journal of Intellectual Disability Research*, **40**(4): 336-347.

Lyall, I., Holland, A. J. and Styles, P. (1995): Incidence of persons with a learning disability detained in police custody: a needs assessment for service development. *Medicine, Science and Law*, 35, 61 – 71.

Mackay, T. (1989). "A community nursing service analysis." *Nursing Standard*, **4**(3): 32-35.

Mansell, J. (1995). "Staffing and staff performance in services for people with severe or profound learning disabilty and serious challenging behaviour." *Journal of Intellectual Disabilty Research*, **39**(1): 3-14.

Mason, J. (1997): People on probation with a learning disability: identification, prevalence and characteristics. Paper given at Seventh DCLP Annual Conference, Cambridge.

Matthews, D. R. (1995). "Challenging service." *Nursing Times*, **91**(23): 59-61.

McCarthy, J. and Boyd, J. (2002): Mental health services and young people with intellectual disability: is it time to do better. *Journal of Intellectual Disability Research*, 46, 3, 250-256.

McConkey, R., Marriot, C. et al. (2002). Specialist assessment and treatment project for people with learning disabilities and additional needs, EHSSB, NHSSB &University of Ulster.

McHaffie, H. and I. Atkinson (1993). "Coping with disability." *Senior Nurse* **13**(2): 43-45.

Meins, W. (1995): Symptoms of major depression in mentally retarded adults. *Journal of Intellectual Disability Research,* 39 (1), 41-45.

Mencap (1999). *The NHS Health for All? People with learning disabilities and health care.* London, Mencap.

Menolascino, F. J. (1988). Mental illness in the mentally retarded: diagnosis and treatment issues. In J. Stark, F. J. Menolascino, M. H. Albarelli and V. Gray (eds.) Mental Retardation *and Mental Health: Classification , Diagnosis, Treatment, Services*. New York, Springer-Verlag: 109-123.

Mental Health Foundation (1996). *Learning Disabilities the Fundamental Facts*. London, Mental Health Foundation.

Morgan, C. L., Zahir, A. et al. (2000). "Health care provision for people with a learning disability." *British Journal of Psychiatry* **176**: 37-41.

Moss, S. (1999a). Assessment and conceptual issues. In N. Bouras (eds.) *Psychiatric and behavioural disorders in development disabilities and mental retardation,* Cambridge: Cambridge University Press. (pp. 18-37),

Moss, S. (1999b). "Assessment of mental health problems" *Tizard Learning Disability Review* **4**(2): 14-19.

Moss, S. C. (1995). "Methodological issues in the diagnosis of psychiatric disorders in adults with learning disabilities." *Thornfield Journal (University of Dublin)*, **18**(9-18).

Moss, S. C., Patel, P. et al. (1993). "Psychiatric morbidity in older people with moderate and severe learning disability mental retardation Part 1 Development and reliability of the patient interview the PAS-ADD." *British Journal of Psychiatry*, **163**: 471–480.

Moss, S., Ibbotson, B. et al. (1996a). "Validity of the PAS-ADD for detecting symptoms in adults with learning disability mental retardation." *British Journal of Psychiatry*, **168**(3): 359-367.

Moss, S., Emerson, E. et al. (1997). " Mental disorders and problem behaviours in people with intellectual disability future directions for research." *Journal of Intellectual Disability Research*, **41**(6): 440-447.

Moss, S., Prosser, H. et al. (1996b). "Respondent and informant accounts of psychiatric symptoms in a sample of patient with learning disability." *Journal of Intellectual Disability Research*, **40**: 457-465.

Moss, S., Prosser, H. et al. (1998). " Reliability and validity of the PAS-ADD Checklist for detecting psychiatric disorders in adults with intellectual disability." *Journal of Intellectual Disability Research*, **42**: 173-183.

Murphy, G. & Fernando, S. (1999): Services for people with challenging and mental health needs at risk of offending. *Tizard Learning Disability Review*, **4** (3), 31 – 39.

Murphy, G. & Mason. J. (1999): In N. Bouras (Eds) *Psychiatric and behavioural disorders in development disabilities and mental retardation*. Cambridge: Cambridge University Press. 226 - 246

Murphy, G. and Wilson, B. (eds.) (1985). *Self injurious behaviour a collection of published papers on prevalence, causes, and treatment of people who are mentally handicapped or autistic*. Kidderminister, British Institute of Mental Handicap Publications.

Naylor, V. and Clifton, M. (1993). "People with learning disabilities - meeting complex needs." *Health and Social Care in the Community*, **1**(6): 343-353.

Newman, I. and Emerson E. (1991). "Specialised treatment units for people with challenging behaviours." *Mental Handicap*, **19**(3): 113-119.

O'Brien, G. (1990). "Current patterns of service provision for the psychiatric needs of mentally handicapped people visiting centres in England and Wales." *Psychiatric Bulletin*, **14**: 6-7.

Oliver, C. and D. Head (1993). Self injurious behaviour: functional analysis and interventions. In R. Jones and C. Eayrs (eds.) *Challenging behaviour and intellectual disability: a psychological perspective*. Avon, BILD: 12-33.

Oliver, C., Murphy, G. et al. (1987). "Self-injurious behaviour in people with mental handicap: a total population survey." *Journal of Mental Deficiency Research*, **31**(2): 147-162.

Parahoo, K. and Barr, O. (1994). "Job satisfaction of community nurses working with people with mental handicap." *Journal of Advanced Nursing*, **20**(6): 1046-1055.

Parahoo, K. and Barr, O. (1996). "Community mental handicap services in Northern Ireland: a profile of clients and selected work practices." *Journal of Clinical Nursing*, **5**(4): 221-228.

Patel, P., Goldberg, D. P. et al. (1993). Psychiatric morbidity in older people with moderate and severe learning disability mental retardation Part 2 The prevalence study. *British Journal of Psychiatry* (163): 481–491.

Persaud, S. and Persaud, M. (2003). " Does it hurt to die? Bereavement to help people with learning disabilities." *Bereavement Care*, **22**(2): 9–11.

Piazza, C. C., Fisher, W. W. et al. (1997). "Treatment of multiple sleep problems in children with developmental disabilities: fading bedtime with response cost versus bedtime scheduling." *Developmental Medicine and Child Neurology* **39**(6): 414-418.

Prosser, H., Moss, S. et al. (1998). "Reliability and validity of the Mini PAS-ADD for assessing psychiatric disorders in adults with intellectual disability." *Journal of Intellectual Disability Research*, **42**: 264-272.

Quigley, A., Murray, G. et al. (2001). " Staff knowledge about symptoms of mental illness in people with learning disabilities." *Journal of Learning disabilities for Nursing, Health and School Health Care* **5**(3): 235-244.

Quine, L. (1991). "Sleep problems in children with mental handicap." *Journal of Mental Deficiency Research* **35**(4): 269-290.

Quine, L. and Pahl, J. (1985). "Examining the causes of stress in families with severely mentally handicapped children." *British Journal of Social Work* **15**(5): 501-517.

Qureshi, H. (1993). Impacts on families: young adults with learning disability who show challenging behaviour. In C. Kiernan (ed.) *Research to practice? Implications of research on the challenging behaviour of people with learning disability.* Clevedon, BILD: 89-115.

Qureshi, H. (1994). The size of the problem. In E. Emerson, P. Mc Gill and J. Mansell (ed.). *Severe learning disabilities and challenging behaviours: Designing high quality services*, Cheltenham: Stanley Thornes Publishers. pp. 17-36

Qureshi, H. and Alborz, A. (1992). "Epidemiology of challenging behaviour." *Mental Handicap Research*, **5**(2): 130-145.

Royal College of Psychiatrists (2001) *DC-LD Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation*. London, Gaskell.

Reed, J. (1990). "Identification and description of adults with mental handicaps showing physically aggressive behaviours." *Mental Handicap Research*, **3**(2): 126-136.

Reiss, S. and Aman, M. (1998): *Psychotropic medications and developmental disabilities. The International Consensus Handbook*. Columbus, OH: The Ohio State University Nisonger Centre.

Reiss, S. and Rojahn, J. (1993): Joint occurrence of depression and aggression in children and adults with mental retardation. *Journal of Intellectual Disability Research*, 37, 287-294.

Reiss, S. (1994): *Handbook of challenging behaviour: mental health aspects of retardation*. IDS Publishing Company: Worthington, Ohio.

Reiss, S., Levitan, G. et al. (1982). "Emotional disturbance and mental retardation diagnostic overshadowing." *American Journal of Mental Deficiency* **86**: 567-74.

Remington, B. (1993). Challenging behaviour in people with severe learning disabilities: behaviour modification or behaviour analysis? In C. Kiernan (ed) *Research to practice?*

Implications of research on the challenging behaviour of people with learning disability. Clevedon, BILD: 119-134.

Ritchie, F. (1993). Opening doors the effects of music therapy with people who have severe learning difficulties and display challenging behaviours. In M. Heal and T. Wigram_(eds,) *Music therapy in health and education*, London, Jessica Kingsley Publishers: 90-102.

Rogders, J. (1994): Primary health care provision for people with learning difficulties. *Health and Social Care in the Community,* 2 (1), 11-17.

Ross, E. and C. Oliver (2002). "The relationship between levels of mood, interest and pleasure and 'challenging behaviour' in adults with severe and profound intellectual disability." *Journal of Intellectual Disability Research*, **46**(3): 191-197.

Rourke, B. P., Young, G. C. et al. (1989). "A childhood learning disability that predisposes those afflicted to adolescent and adult depression and suicide risk." *Journal of Learning Disabilities*, **22**(3): 169-174.

Roy, A. and Cumella, S. (1993): Developing local services for people with a learning disability and a psychiatric disorder. *Psychiatric Bulletin*, 17, 215-217.

Russell, P. (1997). "Don't forget us! Messages from the Mental Health Foundation Committee's Report on Service for Children with Learning Disabilities and Severe Challenging Behaviour." *British Journal of Special Education*, **24**(2): 60-65.

Salovita, T. (2002). "Challenging behaviour, and staff responses to it, in residential environments for people with intellectual disability in Finland." *Journal of Intellectual & Developmental Disability*, **27**(1): 21-30.

Sayre-Adams, J. (1994). "Clinical complementary therapies therapeutic touch: a nursing function." *Nursing Standard,* **8**(17): 25-27.

Schopler, E., Mesibov, G. et al. (1982). "Evaluation of treatment for autistic children and their parents." *Journal of American Academy of Child Psychiatry,* **21**(3): 262-267.

Seager, M., Bell, G. et al. (2000). "Readmission's to learning disability hospitals." *Journal of Learning disabilities for Nursing, Health and School Health Care,* **4**(4): 321–331.

Seideman, R. Y. and Kleine P. F. (1995). "A theory of transformed parenting: parenting a child with developmental delay/mental retardation." *Nursing Research*, **44**(1): 38-44.

Seltzer, M. M., Greenberg, J. S. et al. (1995). "A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation." *Psychology and Aging*, **10**(1): 64-75.

Shapiro, M., Parush, S. et al. (1997). "The efficiency of the "Snoezelen" in the management of children with mental retardation who exhibit maladaptive behaviours." *The British Journal of Developmental Disabilities* **43**(2): 140-153.

Simpson, M. K. & Hogg, J. (2001a): Patterns of offending among people with intellectual disability: A systematic review. Part 1: Methodology and prevalence data. *Journal of Intellectual Disability Research*, 45, 384 – 396.

Simpson, M. K. & Hogg, J. (2001b): Patterns of offending among people with intellectual disability: A systematic review. Part 2: Predisposing factors. *Journal of Intellectual Disability Research*, 45, 397 - 406.

Sines, D., Moore, K. et al. (1996). A Study to Evaluate the TEACCH Project (Treatment and Education of Autistic and related Communication handicapped Children) in the South Eastern Library Board Area of Northern Ireland. Belfast, DHSS & University of Ulster.

Singh, P. (1997): *Prescription for change: A MENCAP report on the role of GP's and carers in the provision of primary care for people with learning disabilities*. London: MENCAP.

Slevin, E. & McClelland, A. (1999) An evaluation of the relaxation effects of multi-sensory therapy in a person with learning disabilities: A single subject quasi-experiment. *Journal of Clinical Nursing*, 8 (1) 48-56

Slevin, E. (1995). "A concept analysis of, and proposed new term for, challenging behaviour." *Journal of Advanced Nursing*, **21**: 928-934.

Slevin, E. (1996). "Interpreting problematic behaviour in people with learning disabilities: 2." *British Journal of Nursing*, **5**(10): 610-627.

Slevin, E. (1998). How do community nurses meet the needs of people who challenge services? A theoretical explication of the role of community nurses for people with learning disabilities. Unpublished D. Phil thesis, University of Ulster.

Slevin, E. and D. Sines (1996). "Attitudes of nurses in a general hospital towards people with learning disabilities: influences of contact, and graduate non-graduate status, a comparative study." *Journal of Advanced Nursing*, **24**(6): 1116-1126.

Slevin, E., Mc Conkey, R. et al. (2002). *A census and investigation of admission trends to Longstone Hospital in Armagh: Information for a new core hospital*, SHSSB & University of Ulster.

Smith, G. C., Tobin, S. S. et al. (1995). "Elderly mothers caring at home for offspring with mental reardation: a model of permanecy planning." *American Journal on Mental Retardation* **99**(5): 487-499.

Stalker, K. (1988). "Family-based respite care for children with severe learning difficulties: an evaluation of the Lothian scheme." *Social Services Research* **17**(1): 1-10.

Stanley, R. (1997). "Assessment and management of pica in adults with learning disabilities." *Mental Health Care*, **1**(4): 125-127.

Stenfert Kroese, B., Dagan, D. et al., eds. (1997). *Cognitive behaviour therapy for people with learning disabilities*. London, Routledge Press.

Sturmey, P. (1999). Classifications concepts, progress and future In N. Bouras (ed.) *Psychiatric and behavioural disorders in development disabilities and mental retardation*. Cambridge, Cambridge University Press: 38–48.

Sturmy, P. (1995). "DSM III-R and persons with dual diagnosis: Conceptual issues and strategies for future research." *Journal of Mental Retardation Research*, **39**: 357-364.

Taggart, L. (2003). Service provision for people with learning disabilities and mental health problems: PhD Thesis: University of Ulster.

Taylor, J. L., Hatton, C. et al. (2004). "Screening for psychiatric symptoms PAS_ADD Checklist norms for adults with intellectual disability." *Journal of Intellectual Disability Research*, **48**(1): 37 – 41.

Toogood, S., Bell, A. et al. (1994a). "Meeting the challenge in Clwyd: the intensive support team part 1." *British Journal of Learning Disabilities*, **22**(1): 18-24.

TOPSS (1999). *England training strategy for social care*. London, National Training Organisation for Social Care.

Trower, T., Treadwell, L. & Bhaumik, S. (1998): Acute in-patient treatment for adults with learning disabilities and mental health problems in a specialised admission unit. *British Journal of Developmental Disabilities*, 86, 20-29.

Turnbull, A. and Turnbull H. (1990). *Families, Professionals, and Exceptionality: A Special Partnership*. Columbus, OH, Merrill.

Vig, S. and Jedrysek E. (1995). "Adaptive behaviour of young urban children with developmental disabilities." *Mental Retardation*, **33**(2): 90-98.

Walsh, R. (1997). "When having means losing." *British Journal of Music Therapy* **11**(1): 13-19.

Wiggs, L. and Store G. (2001). "Behavioural treatment for sleep problems in children with severe intellectual disabilities and daytime challenging behaviour: Effects on mothers and fathers." *The British Journal of Learning Disabilities* **6**(3): 257-269.

Wiggs, L. and Stores, G. (1996). "Severe sleep disturbance and daytime challenging behaviour in children with severe learning disabilities." *Journal of Intellectual Disability Research*, **40**(6): 518-528.

Willoughby, J. C. and Glidden, L. M. (1995). "Fathers helping out: shared child care and marital satisfaction of parents of children with disabilities." *American Journal on Mental Retardation*, **99**(4): 399-406.

Winter, H., Holland, A. J. & Collins, S. (1997): Factors predisposing to suspected offending by adults with self-reported learning disabilities. *Psychological Medicine*, 27, 595 – 607.

Wolfensberger, W. (1994). "The growing threat to the lives of handicapped people in the context of modernistic values." *Disability and Society* **9**(3): 395-412.

World Health Organisation (1996). *ICD 10 Guide for mental retardation. Division of mental health and prevention of substance abuse*: WHO: Geneva.

Wressel, S. E., Tyrer, S. P. et al. (1990). " Reduction in anti-psychotic drug dosage in mentally handicapped patients A hospital study." *British Journal of Psychiatry*, **157**: 101–106.

Xenitidis, K. I., Gratsa, A et al. (2004). "Psychiatric in-patient care for adults with intellectual disabilities generic or specialist units?" *Journal of Intellectual Disability Research*, **48**(1): 11-18.

Xenitidis, K. I., Henry, J. et al. (1999). "An inpatient treatment model for adults with mild intellectual disability and challenging behaviour." *Journal of Intellectual Disability Research*, **43**(2): 128-134.

Zarkowska, E. and Clements, A. (1988). *Problem behaviour in people with severe learning disabilities: a practical guide to a constructional approach*. Beckenham, Croom Helm.

Chapter 8:
Older People with a Learning Disability

Overview

The number of older people is increasing across most developed countries. Over the last 70-80 years the number of people in England for example over age 60 has doubled, and by 2001 over one fifth of the population was over 60 (Scott, et al. 2003). Similar data is not available for Northern Ireland but it is probably not dissimilar.

Life longevity is also increasing with many people now living into their 80s and beyond. The National Service Framework for Older People (Department of Health, 2001) predicts that in the 30-year period (1995-2025) the number of people living to 90 years and beyond will double. This trend, which is due to advances in medical science and social improvements, is also evident in the people with a learning disability (WHO, 2000).

The WHO (1999) views the need for adequate caring services for the ageing population as a crucial matter. As people live longer it is expected that they will become more vulnerable to health problems. However, people with a learning disability are at particular risk (WHO, 2000). The WHO (2000) state:

> *'In many nations, older adults with severe and profound impairments are disregarded or institutionalized. Housing is often inadequate and health provision neglected. Older adults with mild impairments are often marginalized and not provided with minimal supports needed to be productive members of their societies.'*

This review is structured into four Sections.

Section 1 defines old age and the impact ageing has on people with a learning disability in particular.

Section 2 examines the social implications of growing older.

Section 3 reviews information gathered in Northern Ireland.

Section 4 summarises the implications and recommendations for services in meeting the needs of this growing population.

Section 1: Definitions and Impact of Ageing

Growing old is a natural process for everyone and it may seem quite straightforward to define old age. However, a number of key issues do need to be considered. First, the age when one is considered old is linked to the social mores in a particular society. A general guideline might be that the onset of old age is demarcated by when one retires from one's occupation i.e. between 60-65 years in our society. But, this is now becoming more blurred with some people retiring early, and others taking up second careers post retirement. Many people continue to lead full and active lives well beyond the age of 65 years. Secondly, old age may be defined in physical terms i.e. when the biological changes of increased age begin to limit a person's capacity. Finally, old age is psychologically determined. One person may be very happy in their advanced age, while another may go through what can be almost a grief reaction, with a sense of feeling undervalued, worthless and segregated. It may therefore be better to view old age as a state of mind (Ward, 2000).

People with a learning disability

If old age is determined by physical, social and psychological factors, as stated above, the population of people with a learning disability may not 'fit' well into traditional definitions of old age.

If old age is socially constructed this may have little use in determination of when it begins in this population as they are often set aside as a subculture within the society to which they belong. Individuals with a learning disability are restricted socially and have limited social networks (Thorpe, et al. 2000).

The biological aspects of ageing may differ for people with a learning disability in a number of respects. For example, some people such as people with Down's syndrome show signs of ageing in their 30s (Zigman, et al. 2002) ; and life longevity tends to be reduced for people with severe and profound disabilities (Holland 2000; Rice and Robb 2004). Although, some would argue such decline should be kept separate from reduced function as a result of 'normal' ageing (Thorpe et al, 2000). Thorpe et al suggest most adults with a learning disability who live past the third decade are likely to live into old age.

There is limited evidence on how well these people cope psychologically with ageing. It could be that due to cognitive limitations some people find difficulty comprehending the ageing process. This is added to as many individuals with a learning disability are prevented from experiencing normal life events. Thorpe et al (2000) cite acceptance of mortality (an integral aspect of ageing for everyone) to highlight this. They use the example of how people with a learning disability may be hindered in the acceptance of mortality as they are frequently not exposed to rituals such as funerals in an attempt to protect the person from unpleasant events. Such actions may well be doing the individual more harm than good.

Therefore, the social, psychological and biological aspects of aging that everyone encounters may be quite different for many people with a learning disability. It may be more informative and meaningful to identify how this group are affected by ageing than to dwell unnecessarily on how old age is defined.

Impacts of ageing on people with a learning disability

The effects of ageing do eventually impact on everyone. However, for people with a learning disability there are significant differences in relation to the onset of age related difficulties, and there are some problems that are specific to this client group.

Dementia

A number of different types of dementia exist but the most significant and prevalent is Alzheimer's disease. The neurological effects of this disorder are devastating for the person who develops it and for his/her family. It leads to a deterioration in function in virtually all aspects of life, a disintegration of the affected person's personality and eventually death. There is an abundance of research evidence indicating that people with Down's syndrome exhibit neurological changes resulting from Alzheimer's type dementia at a much younger age than others, and in addition virtually all people with Down syndrome who live long enough will develop this type of dementia (Dalton and Janicki, 1999). Table 1 illustrates the percentage of people with Down syndrome with dementia for various age bands. This can be compared with the general population where it is estimated that around 5% of people over 65 years will have dementia, although this percentage increases with advancing age.

Research has found that dementia leads to carers spending much more time in the undertaking of caregiving roles, and the nature of care changes to such aspects as:

- ☐ Supervision, or undertaking for the person, activities of living
- ☐ Having to respond to behavioural problems
- ☐ Much more close attention to safety aspects
- ☐ Disruptions to normal daily life patterns e.g. night-time wakening

(Moss and Patel 1997; Martin, et al. 2000; Oliver, et al. 2000; McCarron, et al. 2002;)

Table 1: Percentage of people with Down's syndrome affected with Alzheimer's Disease (McQuillan, Kalsy et al. 2003)

Age in years	Rate %
30-39	0-10%
40-49	10-30%
50-59	20-55%
60-69	30-75%

Health and Sensory Decline

Although increased longevity is positive it does bring with it inherent needs. It is inevitable that as people live longer they are more likely to become exposed to and develop older-age related health problems (Evenhuis, et al. 2001). These health problems are similar to those experienced by other older people in society (Janicki, et al. 2002). However, people with a learning disability may develop what is known as '*syndrome-specific*' conditions, see Table 2 for an example of some such conditions.

Table 2: An example of syndrome-specific health problems

Syndrome	Syndrome-specific condition		Authors
Down's	Congenital heart defects		Pueschel & Pueschel (1992)
	Gastrointestinal problems		Pueschel & Pueschel (1992)
	Visual and hearing disorders (related to old age)		McVicker, et al. (1994)
	Infections		Marino & Pueschel (1996)
	Decreased longevity		Janicki et al (1999)
Fragile-X	Mitral valve prolapse		Sreeram et al (1989)
	Musculoskeletal problems		Davids et al (1990)
	Early menopause		Conway et al (1998)
	Epilepsy		Ribacoba et al (1995)
Prader-Willi	Obesity related:	Diabetes	Greenswag (1987)
		Heart conditions	Lamb and Johnson (1987)

Other health related needs specific to older people with a learning disability relate to the central nervous system damage associated with the person's initial disability, which can lead to increased vulnerability to conditions such as: epilepsy, cerebral palsy, and some forms of visual impairment (Evenhuis, 2001). There is of course the danger that syndrome-specific health conditions in older people with a learning disability may be perceived as inevitable and therefore little can be done about them. In a survey of 1373 older people with a learning disability Janicki et al (2002) found that over 50% were reported to be obese, yet staff and carers who responded did not see this as a health problem thus suggesting obesity may be considered as an accepted 'norm' for this population.

Janicki et al (2002) also found that sensory impairments (e.g. visual, hearing) were frequently found in the sample surveyed. Sensory impairments may be accepted as part of the normal ageing process but in this survey the age range was ≥ 40-89 with 73% being under the age of 59 (i.e. a younger old age group). As Janicki et al indicate the high levels of sensory impairments in older people with a learning disability has been reported in previous research (Evenhuis 1997; Janicki and Davidson 1998).

Mental health problems and behavioural change

Research indicates that among the population of older people who have a learning disability there is a high incidence of mental health problems (Cooper, 1997; 1999). The prevalence of mental illness varies in people with a learning disablity depending on where the population is drawn from. For example within a hospital for people with a learning disability it was found that 30% of people who were consider long-stay had a psychiatric disorder (Day, 1985). On the other hand Moss and Patel (1993) reported a prevalence figure of 11% with depression and anxiety being the main presenting conditions. Percentage figures can also alter if dementia is included with other mental health problems (see section above on dementia). Overall, Parry (2002) states that depending on the survey and when old age is defined between 20-40% of older persons with a learning disability are liable to have a mental health problem.

The most common behavioural features reported in older people with a learning disability in the literature are dementia-related behavioral changes. Behavioural changes that have been reported include depressive features, wandering, psychotic symptoms and aggression (Donaldson, et al. 1997). It has been reported that challenging behaviours such as aggression are common in older people with dementia (Gardiner, 2002). However, misrepresentation of research results needs to be guarded against. Gardiner references Cooper and Prasher (1998) in support of the claim of increased aggression yet when this study was reviewed it was found that there was no significant increase in aggression in people with Down syndrome and dementia in comparison with others. While adaptive behaviour may decline in people with dementia, behaviours such as aggression are not always present. Two studies reviewed reported no significant increases in aggression in people with Down syndrome and dementia (Cooper and Prasher 1998; Cosgrove, et al. 1999).

Conclusions

Overall, what can be drawn from the literature in this section is that older people tend to have similar general health related problems to other older people. However, some do suffer the additional problems related to ‘syndrome-specific’ disorders and sensory defects associated with the aetiology of their learning disabilities. With regard to mental health a significant number of older people with a learning disability will have mental health problems, this being particularly so in the case of dementia in people with Down’s syndrome.

Section 2: Social Factors, Inclusion/Exclusion & Policy Issues

The impact of the various health needs of older people with a learning disability can have far reaching affects for their family (carer), service commissioners and providers, and policy makers.

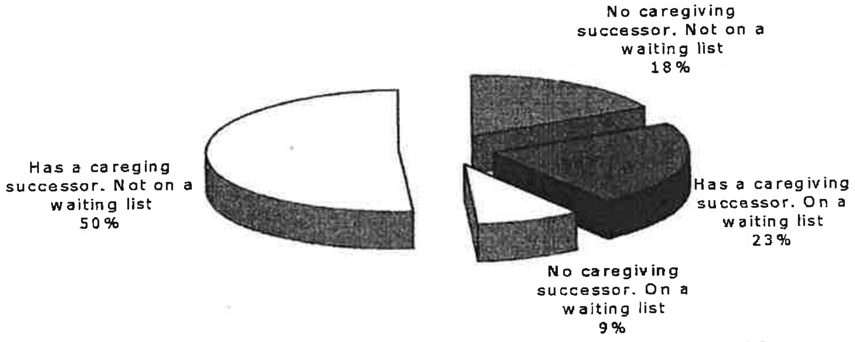
Family carers

As can be seen above age related health needs may arise in older people with a learning disability at a younger age than others (typically from ≥ 50 years). This being the case many of the parents of such individuals may be still alive and acting as their main carer. It is estimated that 30,000 family members in the UK over the age of 60 years are fulfilling caring roles for a relative with a learning disability at home, most (90%) being women (Lambe and Hogg 2003). Interestingly research has found that these older carers cope well and are reluctant to relinquish their caring roles (Krauss and Seltzer 1993). In this study of older carers it was unexpectedly found that the ageing carers coped very well (as well if not better than others) and explanations for not wishing to relinquish their caring role were suggested as being due to the following factors:

- ☐ Parents self-select to care for their son/daughter rather than having them placed in care
- ☐ After many years of caring parents adjust and accommodate to the caring role
- ☐ Parents build a long-term relationship with their son/daughter and do in fact gain and feel they have a purpose in life full-filling the caring role.

With regard to future planning in this study of older carers (387 families) Krauss and Seltzer found that only 9% anticipated an out of home placement for their son or daughter, most seemed to have planned well for the future.

Figure 1: Long-term plans of caring mothers of adults with learning disabilites



The Figure above cited in Krauss & Seltzer (1993, 54) illustrates this. These findings by Krauss and Seltzer (1993) demonstrating the resilience of older carers is somewhat surprising in view of the many burdens on carers that have been identified (see Chapter 7 also).

Lambe and Hogg (1995) suggest the term that best describes the commitment of these cares is '*acceptance*'. Older people with a learning disability who lose their primary carer, usually a parent, often lack having children of their own to help meet their needs and they do not always have a sibling to care for them (Ashman, et al. 1993). Many older people with a learning disability are left in a position where they have no other family member to care for them, Gibson, et al. (1992) use the term 'familyless elderly' to describe this group. Bigby (1997) states service providers usually take on the key role of primary carer for these older people when they loss their primary carer, even though some might have contact with significant others.

Policy issues and social exclusion

As can be seen in previous sections of this review older people with a learning disability have a number of specific health and social needs. These are in addition to the needs common to all older people and the growing recognition of '*ageism*' in many societies (Slevin, 2003). However, among this population older people have been found to have additional high rates of untreated illness and under use of health services (Wilson and Haire 1990; Howells 1996; Patel, et al. 1993;).

In a study undertaken by Cooper (1997b) it is reported that older people with a learning disability received less:

☐ Day care

☐ Respite care

☐ Were less likely to have a social worker

☐ Received less input from most health services.

Many older people in general enjoy an active social life and some take on new careers. However, for the older person with a learning disability few have opportunities to take part in leisure pursuits (Rogers, et al. 1998). This is due to the health problems they face, perceptions of them as a lower social status group, exclusion rather than inclusive within their community and lack of support to access leisure activities (Browder and Cooper 1994). Not surprisingly, when access to leisure is so difficult for these people the chances of obtaining employment is even more difficult, in fact many have never had meaningful employment when they were younger (Ashman, et al. 1995).

If social inclusion is an underpinning philosophy of contemporary health and social care then questions need to be asked regarding the under-use of health and social services, leisure and occupational pursuits by older people with a learning disability. It seems that efforts to initiate inclusion have failed older people with a learning disability (Hogg, 1997). Even setting aside the issue of social inclusion it may be that older people are excluded from services within learning disabilities per se i.e. day care, respite and access to a social worker.

Robertson, et al. (1996) analysed community care plans from 1993/94 and found: 67% made no reference to older people with a learning disability; the remaining 33% made mention of older people only with respect to future policy; in 236 replies to a national survey they conducted in Britain 82% reported there was no policy in relation to older people with a learning disability.

Policies are now beginning to recognize the growing needs of older people, and their ageing carers. Valuing People (DoH, 2001) states that 25% of people with a learning disability only become known to statutory agencies in later life. This report also suggests there is a need to prioritize person-centred planning with people who live with older carers. However, in a survey for the Foundation for People with Learning Disabilities (FPLD, 2003) it is stated that the monitoring of needs of older family carers is ad hoc and poor. It seems that while policy directives aim for improvements in care such suggested improvements are slow to filter through to practice for this client group.

Conclusions

Family carers still bear the bulk of caring even when their relatives are elderly. Service commissioners and providers have been slow to develop policies and practices that address the needs of this population.

Section 3: Northern Ireland

Interest and research into the needs of older people with a learning disability is a relatively recent phenomenon. Within Northern Ireland there has been limited research that has focused directly on this client group. However, there are some studies which have identified need regarding older people with a learning disability.

Numbers

A recent prevalence study of people with a learning disability in Northern Ireland (McConkey, et al. 2003) identified the following:

- Out of 4,107 people with a learning disability living in ordinary homes 477 (12%) are aged over 60 years of age (see Appendix 8.1: Figure 1). Planning for the needs of older people with a learning disability should begin much earlier. Rice and Robb (2004) suggest it may need to begin at age 50 for some people due to various needs that have been identified in this review. If we applied this to McConkey's et al. figures then 1219 (30%) of these 4,107 people could be considered to fall within the older adult population.
- In Figure 2 (Appendix 8.1) McConkey et al (2003) identify the number of people with a learning disability living in residential or supported living. These figures show that of 1,358 people in supported/residential living; 375 were ≥ 60 years of age and if we consider the age of 50 (due to reasons above) as representing older age then ≥ 50 is 712 (52%) of these people who can be considered older adults with a learning disability.
- Figure 3 (Appendix 8.1) taken from McConkey et al (2003) identify the number of people with a learning disability who are long-stay in hospitals (defined as longer than one year). This shows there are 435 long-stay people in the hospitals in Northern Ireland. Of these people 53 (12%) are aged 65 years and over and one third of the hospital residents (285, 66%) are aged 45 years and older.
- Figure 4 (Appendix 8.1) presents figures from another study in Northern Ireland that investigated future housing needs in one board area (McConkey, 2003b). Figure 4 illustrates that 37% of carers for adults with a a learning disability are over 65 years old. McConkey projects this to the other data presented and estimates that nearly 500 people live with a carer over 75 years of age and a further 1,000 persons with a carer aged 65 years.

Other studies have investigated the biographical details of hospital populations of people with a learning disability in Northern Ireland (McConkey, et al. 2002; Slevin, et al. 2002). The age population of this group of people are reflected in Figure 4 (Appendix 8.3) and have been discussed under McConkey's et al (2003) study above.

In one H&SSB area in Northern Ireland it was found that there was 217 families caring for people with severe learning disabilities where the mother was the sole carer, in contrast only 30 fathers held this role. In other words the mother was seven times more likely to be the sole carer than the father (McDonald and Mackay, 1997). This finding is supported in this review where previous research located also indicates that mothers are the main carers in most caring families.

McDonald and Mackay (1996) also investigated the prevalence of severe learning disability in Northern Ireland and found there to be differences in prevalence figures with a west/south – north/east divide i.e. there were higher prevalence figures for severe learning disabilities in the SHSSB and WHSSB areas in Northern Ireland. There is a need for further investigation into this uneven prevalence spread and any such investigation should identify if this is also the case for older people with a learning disability.

Dementia

In a study in the EHSSB (Davies, et al. 2003) the authors undertook a needs assessment of people with a learning disability and dementia. They identified 43 people ; 42% had dementia, 9% were being assessed for the condition and 44% were considered by their key workers to be showing signs of dementia. 36 of these people were ≥ 51 year of age and 26 people had Down's syndrome (each person being aged < 65 years). In addition to identifying the prevalence of dementia Davies et al (2003) also identified current, and future need and present difficulties for these people across their various residences, these are summarised in Table 3.

Maybin (2002) in a survey of 44 older carers in one HSS trust found that deterioration in mobility of their ageing relative was the most common problem followed by the onset of epilepsy; reported by 45% and 33% of carers respectively. Most of their support came from social workers and GPs but rarely more than a visit once every six months to one year. Carers expressed little interest in knowing more about learning disability and dementia which may stem from an ignorance on their part about what this means. This were reluctance to attend formal training sessions preferring instead to have personal contacts or leaflets.

Conclusions

Although Northern Irish research is sparse in this area, the studies that have been undertaken tend to support the findings from elsewhere. As yet, specialised services for this client group with dementia are non-existent although the some of the elements of them have been described by a report prepared by the one HSS trust (Maybin 2002) . This theme will be develop further in the next section.

Table 3: Needs identified for a group of people with dementia in the EHSSB
(source Davis et al 2003)

Residence →	***Own Home***	***Residential Home***	***Nursing Home***
Suggested Need			
Current	Decreased mobility Confusion Sleep disturbance Supervision Vulnerable physical and mental state	Managing safe environment	Facilities not suitable Disorientation
Issues to be addressed now	Carer stress Carer not able to manage behaviour Carer's age Progressive incontinence House adaptation	Increasing physical & emotional care Increasing support Incontinence Higher ratio of staff	Increasing dependency on personal care and feeding
Anticipated	Respite for carer Constant care – residential/nursing Specialist unit Inability of carer to manage	Nursing care	Diagnosis Challenging behaviour

Section 4: Implications and Recommendations

The National Service Framework for Older People (DoH, 2001) relates to all people over 65 living in England. However, this age limit may exclude many people with a learning disability. Planning for the needs of these older people should begin much earlier, Rice and Robb (2004) suggest it may need to begin at age 50 for some people. This seems a logical argument and it is supported by the findings in this review where it is identified that older people with a learning disability are exposed to the same age-related health risks as others. But, additionally people with a learning disability typically develop age-related problems at a younger age than others; they are vulnerable to syndrome-specific, genetically induced and cognitively related difficulties. If 50 years of age is accepted as a defining age for old age monitoring of older people with a learning then the prevalence of older adults with this disability would increase significantly. This would be positive in a number of respects:

- ☐ The higher prevalence would lead to a stronger case for resource claims to meet the needs of this group
- ☐ Monitoring would allow early identification of potential problems and thus improved planning to meet this growing need
- ☐ Many potential crisis management situations could be avoided
- ☐ Service user and family education and preparation for growing old could be planned for earlier and therefore be more effective.

Practice guidelines

There has been a proliferation in recent years of the development of good practice guidelines across many areas of health and social care, these have been given more exigency by the clinical and social care governance agendas. Terms utilised include; clinical effectiveness, evidence-based practice, care pathways, clinical guidelines and best practice guidelines. These can be very useful to guide practice but before presenting some practice guidelines a word of caution is stated here. Practice guidelines are exactly what they state i.e. 'guidelines' and they should not be mistaken for 'rule based' directives. Practice guidelines can be very useful provided that this principle is kept in mind. The danger is that such guidelines lead to *'off the shelf'* practice with people being made to fit into the practice provided, rather than as it should be i.e. practice being individualized and based on individual assessment of need. Keeping this in mind there are some useful practice guidelines for service delivery to older people with a learning disability that can be integrated within individual person-centred plans.

Janicki, et al. (1995) (reproduced in Janicki, et al. 1996) in a workgroup for the AAMD have identified practice guidelines for the care of older people with a learning disability who have dementia, these include:

Identification

- ☐ Workers in adult services should be familiar with normal and pathological ageing processes
- ☐ Those who are at risk (e.g. people with Down syndrome) need to have periodic screening

- ☐ Staff need to be able to recognize early behavioural & clinical signs of dementia, which differ in the this population e.g. memory loss (a usual first sign of dementia) may not present as such in a person with Down syndrome. More typical signs might be: new onset of seizures, personality change, loss of self care skills and apathy.
- ☐ A periodically used screening instrument should be used to establish behavioural baselines and thus facilitate future monitoring.
- ☐ Baseline monitoring should begin by at least age 40 in people with Down syndrome, and age 50 in others.

Conducting assessments and evaluations

- ☐ Information should be collected to confirm
- ☐ Continuing monitoring should take place
- ☐ Referral for diagnosis takes place
- ☐ Possible and probable diagnosis should be made based on criteria adapted from McKhann, et al. (1984) and included in the working guidelines of Janicki et al (1995).
- ☐ Detailed medical history informed by family member of clients key worker and involving the person his/her self as much as possible
- ☐ Physical and neurological examination and sensory testing
- ☐ Psychiatric assessment
- ☐ Appropriate diagnostic evaluations such as; EEG, MRI, CTT, X-rays, & pharmacological reviews to rule out overdosage or side effects.
- ☐ Regular periodic assessment of activities of living (as appropriate for a person's degree of learning disability).
- ☐ Referral to specialist services such as gerontology

Instituting medical and care management

- ☐ Systematic treatment of all treatable medical conditions (should be as thorough as it would be for any member of the general population)
- ☐ Treatment of mental disorders such as depression (should be as thorough as it would be for any member of the general population)
- ☐ Frequent review of medications
- ☐ With progress of the dementia all functions will diminish and the person will require intensive support and nursing care
- ☐ Care management path involving documented & implemented strategies through all stages of the disease to include;
    1. Preservation of maximum function
    2. Interventions and support relevant for various stages of condition
    3. Multidisciplinary care planning

☐ Keeping family, friends and companions involved and informed as appropriate.

Education and training

☐ Training should be provided to care staff & family carers

Hogg and Lambe (1999) make the following recommendations regarding older carers:

☐ Services should support older family caregivers and engage in collaborative planning with them

☐ Service managers need to understand the nature and demands of caregiving

☐ Future planning should be sensitive to caregivers and older caregivers in particular

☐ Expert input will be required but parent support and networking with each other is valuable

☐ Cultural considerations of caregivers must be valued and respected.

Service Principles

Wilkenson and Janicki (2001) set internationally agreed principles and guidelines which they named the 'Edinburgh Principles' at a special meeting to define internationally applicable working practices for community supports for adults with a learning disability who have Alzheimer disease. These are summarised below:

Edinburgh Principles

☐ An operational policy that promotes the utmost quality of life

☐ Affirm that strengths, capabilities, skills and wishes should be the overriding consideration in any decision making

☐ Plan and provide supports and services that optimize remaining in the chosen home

☐ Ensure that generic, cooperative, and proactive strategic planning across relevant policy, provider & advocacy groups involves consideration of the current and future needs of the adult with a learning disability affected by dementia

(Note there are 7 main principles identified under the Edinburgh Principles 4 are listed here - excluded are guidelines that mirror those of Janicki et al above – refer to Wilkenson et al for the full listing)

Thorpe et al (2000) also state a number of principles that should be paramount in interventions for older people with a learning disability, these include:

☐ To develop living environments that are responsive to the mental health needs of the older person with a learning disability

☐ To promote mental health and minimize the affects of mental health problems

☐ To increase mental health services and supports in the community for this client group

- ☐ To collaborate with older people with a learning disability & their support systems in developing culturally sensitive, humane… interventions with an integrated [holistic] orientation
- ☐ To improve the quality of life in older people with a learning disability
- ☐ To develop a research agenda to provide evidence concerning each of these goals for all nations

(for a full discussion on these goals see Thorpe et al, 2000).

For guidelines on more practical aspects of meeting the needs of older people with dementia the reader should refer to McCarron (1999) who discusses:

- ☐ Making meal times a therapeutic event
- ☐ Using reality orientation (RO) in a sensitive therapeutic and caring way
- ☐ Validation techniques & ways to respond to confused people
- ☐ Leisure and entertainment to include:
  - Activities to achieve goals related to cognition, physical activity, social roles, psychological & spiritual well-being & self care
  - Activities that balance sensory stimulation with sensory calming
  - Activities that maximize functioning
- ☐ Encourage clients to set their own pace which can range from observation through to participation
- ☐ Finding alternative means of communication

(adapted from McCarron, 1999, 126-128).

Physical health

Most of the above principles and practice guidelines apply to dementia and focus on mental health, no such principles were located in this review with regard to physical health in older people with a learning disability. However, many of the good practice guidelines above apply equally to physical health. Broadly speaking it is recommended that these older people are offered the following:

- ☐ Regular physical assessments and health checks, at a minimum similar to others in society but due to their additional needs more monitoring might be required
- ☐ Treatments should not be with-held or delayed to anyone based on their age or the extent of their learning disability.
- ☐ Choice and informed consent should be a guiding principle.
- ☐ Access to the full range of primary, secondary & intermediary (step-down and step-up) care should be as a freely available as it is for others in society when required
- ☐ Collaborative shared care should take place (involving both client & family)
- ☐ Older people should not be forgotten with respect to health monitoring & promotion

- ☐ Care staff and professionals should be skilled to undertake health assessments at least to a level to allow recognition of health problems & the need for referral to an appropriate health professional

Education

There is a need emerging, which is evident from this review, to suggest consideration of joint working between the universities and service providers on a number of fronts that might include:

1. Ongoing advice of an in-service nature and short course provision of programmes that will prepare professionals to work with older people with a learning disability
2. Consideration of specialist course provision in gerontology practice in learning disabilities (to include dementia care)
3. To prepare front-line staff to be educators who are skilled at teaching carers
4. To ensure current learning disabilities education programmes include within curriculums appropriate content on working with older people who have a learning disability

Research

It is evident from this review that there is a need for a significant research programme within Northern Ireland on many aspects related to older people with a learning disability. Some of the research that has been cited in this review is extremely useful, especially McConkey's et al (2003) prevalence work that will make a significant contribution to future needs planning. However, there remains a paucity of research on the needs of older people with a learning disability in NI. If significant progress is to be made much more research needs to be commissioned in this area. A significant amount of the research that is presented in this review is national or international, and while undoubtedly some of this offers useful guidance to the local area, how much generalization can be made to NI is not always evident.

Conclusions

This review has synthesized the available evidence on the needs, care provision and identified problems of the older aged population of people with a learning disability. A number of assertions can be confidently made and among these are; that these older people are exposed to the same health and social challenges that face other older people in society, but that some of this client group are faced with additional needs related to their learning disability. Among these additional needs are syndrome-specific health problems, mental heath needs that are at least similar to the general population, and in the case of dementia for some groups such as people with Down's syndrome significantly higher than the general population.

Some questions are forwarded for consideration and debate. The main argument to consider is that the normal convention of defining the beginning of old age as the age of retirement (65 years) has limited utility for people with a learning disability. The proposition for consideration is that learning disabilities services should consider lowering the age of their defined elderly population to 50 years for the purposes of health and social services planning.

The review highlights the current, and potential projected, needs of older caregivers. There is a need for identification and continued monitoring of this group of carers as evidence suggests they many only come to the attention of services when care breaks down.

A number of 'good practice guidelines' that it is suggested will be useful to guide services here in the absence of guidelines based on local need are presented. The review concludes by detailed suggestions regarding education and research to meet future need.

Finally, the words of Turner, 1972 (cited in Slevin, 2003, 409) are presented as a poignant reminder of how we all might feel at some stage in old age, and how significant kindness, respect, interest and dignity can be to an old person (with or without a learning disablity):

> *"If an old man sees that you are really interested in his personal life, you will see a wonderful transformation take place in him. His eyes that seemed dull will light up with a new fire; his face will come alive with unexpected emotion. He felt he had been thrown on the scrap-heap, and all at once he comes to life again, becomes a person once more. Just like the child, the old man needs to be spoken to and listened to in order to become a person, to become aware of himself, to live and grow. You will have brought about something that no social service can ever do of itself; you will have promoted him to the rank of person"*
>
> *(Turner, 1972).*

References

Ashman, A., Suttie, J. et al. (1993). Older Australians with an intellectual disability, A Report to the Department of Health and Housing and Community Services. Queensland, Queensland University.

Ashman, A. F.,. Sutti, J et al. (1995). "Employment, retirement and elderly persons with an intellectual disability." *Journal of Intellectual Disability Research,* **39**(2): 107-115.

Bigby, C. (1997). "When parents relinquish care: Informal support networks of older people with intellectual disabilities." *Journal of Applied Research in Intellectual disabilities* **10**(**4**): 333-334.

Browder, D. M. and K. J. Cooper (1994). "Inclusion of older adults with mental retardation in leisure opportunities." *Mental Retardation*, **32**(2): 91-99.

Conway, G. S., N. N. Payne, et al. (1998). "Fragile X premutation screening in women with premature ovarian failure." *Human Reproduction* **13**: 1184-1187.

Cooper, S. A. (1997). "Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities." *British Journal of Psychiatry* **170**(375-380).

Cooper, S. A. (1997b). "Deficient health and social services for elderly people with learning disabilities." *Journal of Intellectual Disability Research* **41**(4): 331-338.

Cooper, S. A. (1999). "The relationship between psychiatric and physical health in elderly people with intellectual disability." *Journal of Intellectual Disability Research* **43**(1): 54-60.

Cooper, S. A. and V. P. Prasher (1998). "Maladaptive behaviours and symptoms of dementia in adults with Down's syndrome compared with adults with intellectual disabilities of other aetiologies." *Journal of Intellectual Disability Research* **42**: 293-300.

Cosgrove, M. P., J. Tyrell, et al. (1999). "Determinants of aggression, and adaptive and maladaptive behaviour in older people with Down's syndrome with and without dementia." *Journal of Intellectual Disability Research* **43**(5): 393-399.

Dalton, A. and M. Janicki (1999). *Aging and dementia. Dementia, aging and intellectual disabilities*. M. Janicki and A. Dalton. Philadelphia, Brunner/Mazel: 5-39.

Davids, J. R., R. J. Hagerman, et al. (1990). "Orthopedic aspects of fragile-X syndrome." *Journal of Bone and Joint Surgery* **72**: 889-896.

Davies, M., A. McGlade, et al. (2003). "A needs assessment of people in the Eastern Health and Social Services Board (Northern Ireland) with intellectual disability and dementia." *Journal of Learning Disabilities* **6**(1): 23-33.

Day, K. (1985). "Psychiatric disorder in the middle-aged and elderly mentally handicapped." *British Journal of Psychiatry* **147**(660-667).

DoH (2001). *National Service Framework for Older People*. London, DoH.

DoH (2001). *Valuing people: A Strategy for Learning Disability in the 21st century*. London, HMSO.

Donaldson, C., N. Tarrier, et al. (1997). "The impact of the symptoms of dementia on caregivers." *British Journal of Psychiatry* **170**: 62-68.

Evenhuis, H. (1997). "Medical aspects of ageing in a population with intellectual disabilities. III. Mobility internal conditions and cancer." *Journal of Intellectual Disability Research* **41**: 8-18.

Evenhuis, H., C. M. Henderson, et al. (2001). "Healthy Ageing - Adults with Intellectual disabilities: Physical Health Issues." *Journal of Applied Research in Intellectual Disabilities* **14**(175-194).

FPLD and F. f. P. w. L. Disabilities) (2003). Planning for Tomorrow. www.learningdisabilities.org.uk, Foundation for People with Learning Disabilities.

Gardiner, W. I. (2002). *Behavioural challenges in the older adult: a case formulation model for integrating psychiatric and psychosocial diagnosis and treatments. Psychiatric problems in older persons with developmental disabilities*. J. R. Parry. New York, NADD (National Association for the Dually Diagnosed): 5-24.

Gibson, J., J. Rabkin, et al. (1992). "Critical issues in serving the developmentally disabled elderly." *Journal of Gerontological Social Work* **19**: 35-49.

Greenswag, L. R. (1987). "Adults with Prader-Willi syndrome: a survey of 232 cases." *Developmental Medicine and Child Neurology* **29**: 145-152.

Hogg, J. (1997). "Intellectual disability and ageing: ecological perspectives from recent research." *Journal of Intellectual Disability Research* **41**(2): 136-143.

Holland, A. J. (2000). "Ageing and learning disability." *British Journal of Psychiatry* **176**: 26-31.

Howells, G. (1996). "Situations vacant: doctors required to provide care for people with learning disabilities." *British Journal of General Practice* **46**: 59-60.

Janicki, M. P. and P. W. Davidson (1998). "Sensory impairments among older adults with intellectual disabilities." *Journal of Intellectual and Developmental Disability Research* **23**: 3-11.

Janicki, M. P., P. W. Davidson, et al. (2002). "Health characteristics and health services utilization in older adults with intellectual disability living in community residences." *Journal of Intellectual Disability Research* **46**(4): 287-298.

Janicki, M. P., T. Heller, et al. (1995). *Practice guidelines for the clinical assessment and care management or Alzheimer dementias among adults with mental retardation*. Washington, American Association on Mental Retardation.

Janicki, M. P., T. Heller, et al. (1996). "Practice guidelines for the clinical assessment and care management or Alzheimer's disease and other dementias among adults with intellectual disability." *Journal of Intellectual Disability Research* **40**(4): 374-382.

Krauss, M. W. and M. M. Seltzer (1993). "Current well-being and future plans for older caregiving mothers." *The Irish Journal of Psychology* **14**(1): 48-63.

Lamb, A. S. and W. M. Johnson (1987). "Premature coronary artery atherosclerosis in a patient with Prader-Willi syndrome." *American Journal of Medical Genetics* **28**: 873-880.

Lambe, L. and J. Hogg (1995). *Their face to the wind: Service development for older people with learning disabilities*. Glasgow, Enable.

Lambe, L. and J. Hogg (2003). *Older people with learning disabilities* (1999, Updated 2003). www.learningdisabilities.org.uk, Foundation for People with Learning Disabilities.

Marino, B. and S. M. Pueschel, Eds. (1996). *Heart disease in persons with Down syndrome*. Baltimore, MD, Paul H Brookes.

Martin, D. B., M. Dugue, et al. (2000). "The caregiver activity survey (CAS): Longitudinal validation of an instrument that measures time spent caregiving for individuals with Alzheimer's disease." *International Journal of Geriatric Psychiatry* **15**: 680-686.

McConkey, R., C. Marriot, et al. (2002). Specialist assessment and treatment project for people with learning disabilities and additional needs, EHSSB, NHSSB & University of Ulster.

McCarron, M. (1999). "Some issues in caring for people with dual diagnosis of Down's syndrome and Alzheimer's dementia." *Journal of Learning Disabilities for Nursing Health and Social Care* **3**(3): 123-129.

McCarron, M., M. Gill, et al. (2002). "Time spent caregiving for persons with the dual disability of Down's syndrome and Alzheimer's dementia." *Journal of Learning Disabilities* **6**(3): 263-279.

McConkey, R., M. Spollen, et al. (2003). *Administrative Prevalence of Learning Disability in Northern Ireland*. Belfast, DHSS&PS.

McConkey, R. e. a. (2003b). Future Housing and Support Needs of People with Learning Disability in EHSSB area. Belfast, NIHE/EHSSB.

McDonald, G. and D. N. Mackay (1996). "The prevalence of learning disability in a Health and Social Services Board in Northern Ireland." *Journal of Intellectual Disability Research* **40**(6): 550-556.

McKhann, G., D. Drachman, et al. (1984). "Clinical diagnosis of Alzheimer's disease: Report of the NINCDS-ADRDA work group under the auspices of the Department of Health and Human Services Task Force on Alzheimer's Disease." *Neurology* **34**: 939-944.

McQuillan, S., S. Kalsy, et al. (2003). "Adults with Down's syndrome and Alzheimer's Disease." *The Learning Disability Review* **8**(4): 4-13.

McVicker, R. W., O. E. O. Shanks, et al. (1994). "Prevalence and associated features of epilepsy in adults with Down's syndrome." *British Journal of Psychiatry* **164**: 528-532.

Maybin, M. (2002) Report of the Group on older people with learning disabilities. Unpublished paper, Ulster Community and Hospitals Trust.

Moss, S. and P. Patel (1993). "The prevalence of mental illness in people with intellectual disability over 50 years of age, and the diagnostic importance of information for carers." *The Irish Journal of Psychology* **14**(1): 110-129.

Moss, S. C. and P. Patel (1997). "Dementia in older people with intellectual disability: Symptoms of physical and mental illness, and levels of adaptive behaviour." *Journal of Intellectual Disability Research* **41**(1): 60-69.

Oliver, C., L. Crayton, et al. (2000). "Cognitive deterioration in Adults with Down syndrome: Effects on the individual caregivers, and service user." *American Journal on Mental Retardation* **105**(6): 455-465.

Parry, J. R., Ed. (2002). *Overview of mental health problems in elderly persons with developmental disabilities*. New York, NADD (National Association for the Dually Diagnosed).

Patel, P., D. Goldberg, et al. (1993). "Psychiatric morbidity in older people with moderate and severe learning disabilities II: The prevalence study." *British Journal of Psychiatry* **163**: 481-491.

Pueschel, S. M. and J. K. Pueschel, Eds. (1992). *Biomedical concerns in persons with Down Syndrome*. Baltimore, MD, Paul H Brookes.

Ribacoba, M. R., P. J. Salas, et al. (1995). "Fragile X syndrome and epilepsy." *Neuralgia*(10): 70-75.

Rice, J. and A. Robb (2004). "Learning to listen." *Nursing Older people* **15**(10): 10-13.

Robertson, J., S. Moss, et al. (1996). "Policy, services and staff training for older people with intellectual disability in the UK." *Journal of Applied Research in Intellectual Disabilities* **9**(2): 91-100.

Rogers, N. B., B. A. Hawkins, et al. (1998). "The nature of leisure in the lives of older adults with intellectual disabilities." *Journal of Intellectual Disability Research* **42**(2): 122-130.

Scott, P., M. Calamari, et al. (2003). "Autonomy, privacy and informed consent 3: elderly care perspective." *British Journal of Nursing* **12**(3): 158-168.

Slevin, E., R. McConkey, et al. (2002). A census and investigation of admission trends to Longstone Hospital in Armagh: Information for a new core hospital, SHSSB & University of Ulster.

Slevin, O. (2003). A nursing perspective on older people: the problem of ageism. *Theory and practice of nursing*. L. Basford and O. Slevin. Cheltenham, Nelson Thornes: 409-426.

Sreeram, N., C. Wren, et al. (1989). "Cardiac abnormalities in the fragile X syndrome." *British Heart Journal* **61**: 289-291.

Thorpe, L., P. Davidson, et al. (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Biobehavioural Issues.* Geneva, Switzerland, WHO.

Ward, D. (2000). "Adult/Elderly Care Nursing, Ageism and the abuse of older people in health and social care." *British Journal of Nursing* **9**(9): 560-563.

WHO (1999). *Ageing. Exploding the Myths.* Geneva, Switzerland, World Health Organization.

WHO (2000). *Ageing and Intellectual Disabilities - Improving Longevity and Promoting Healthy Aging: Summative Report.* Geneva, Switzerland, World Health Organization.

Wilkenson, H. and M. P. Janicki (2001). *The Edinburgh Principles with Accompanying Guidelines and Recommendations. Edinburgh*, Universities of Stirling (Scotland); Albany, Illinois & Chicago (USA).

Wilson, D. N. and A. Haire (1990). "Health care screening for people with mental handicap living in the community." *British Medical Journal*, **301**(1379-1381).

Zigman, W. B., N. Schupf, et al. (2002). "Incidence and temporal patterns of adaptive behaviour change in adults with mental retardation." *American Journal on Mental Retardation* **107**: 161-174.

Appendix 8.1:
The age distribution of people with a learning disability recorded on Trust information systems.

Figure 1: The number of people living in community settings (i.e. with family carers; own accommodation) in five-year age bands. (N=4107)

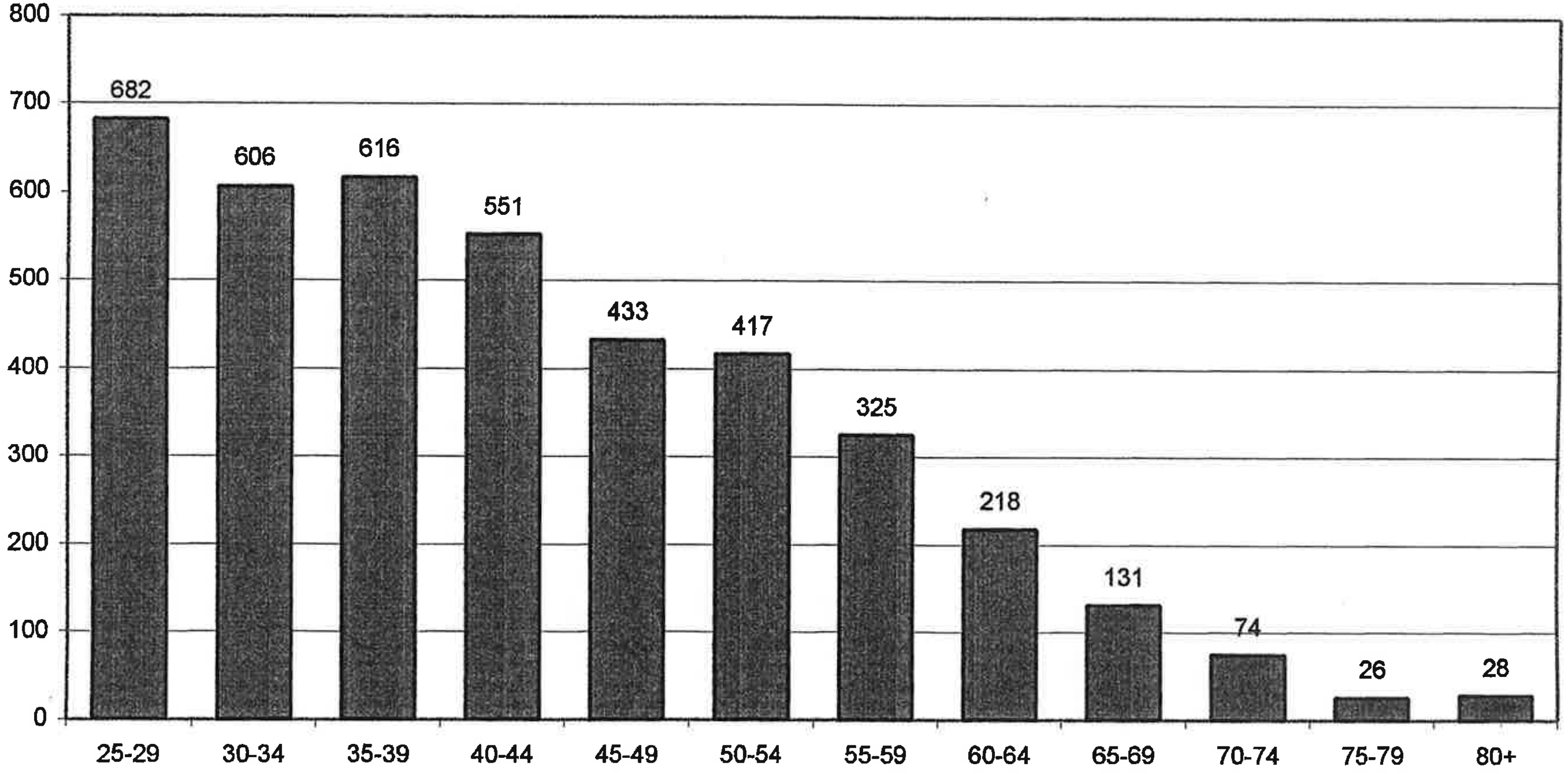


Figure 2: The number of people living in residential and supported living settings in five-year age bands (N=1358)

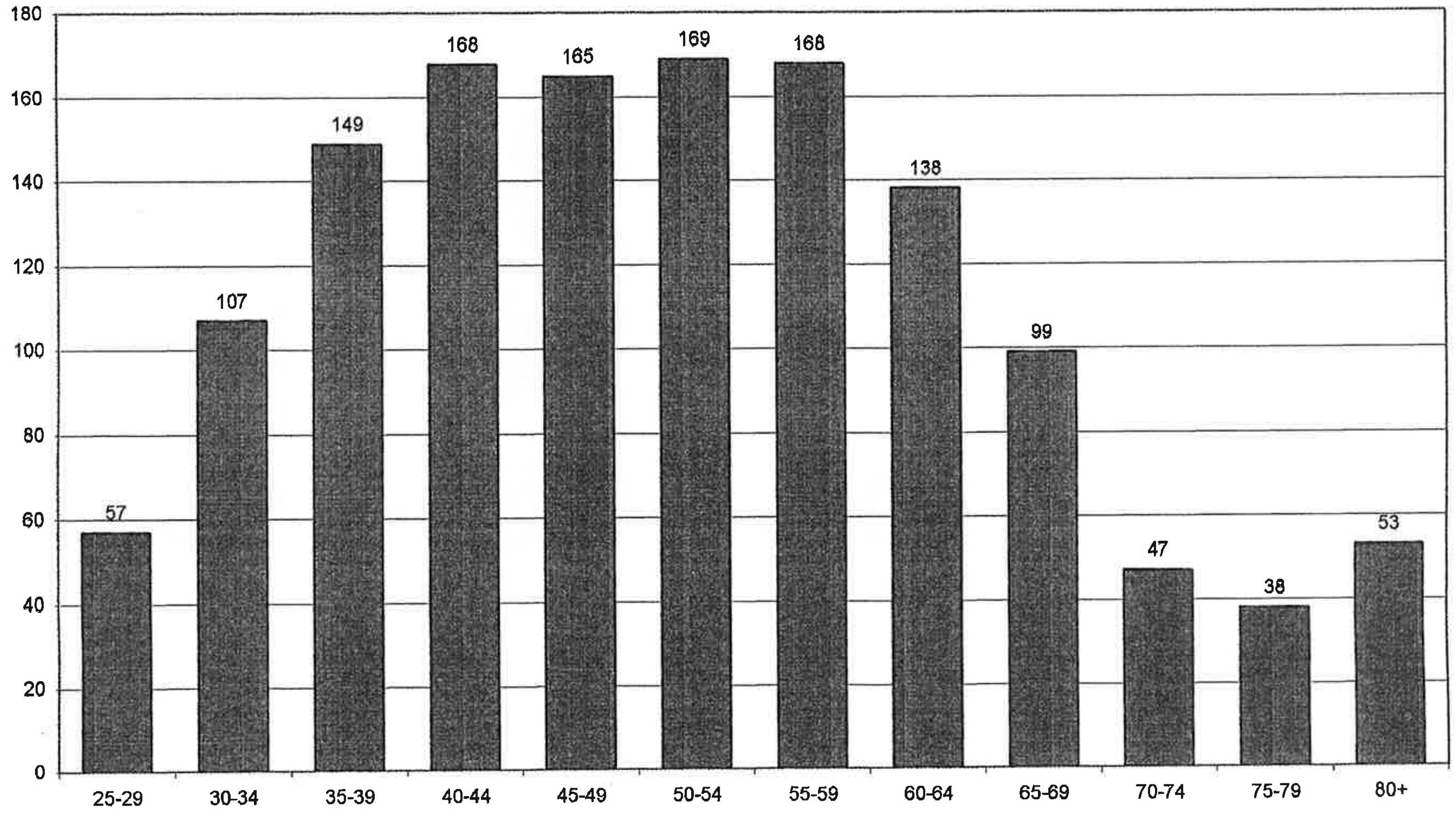
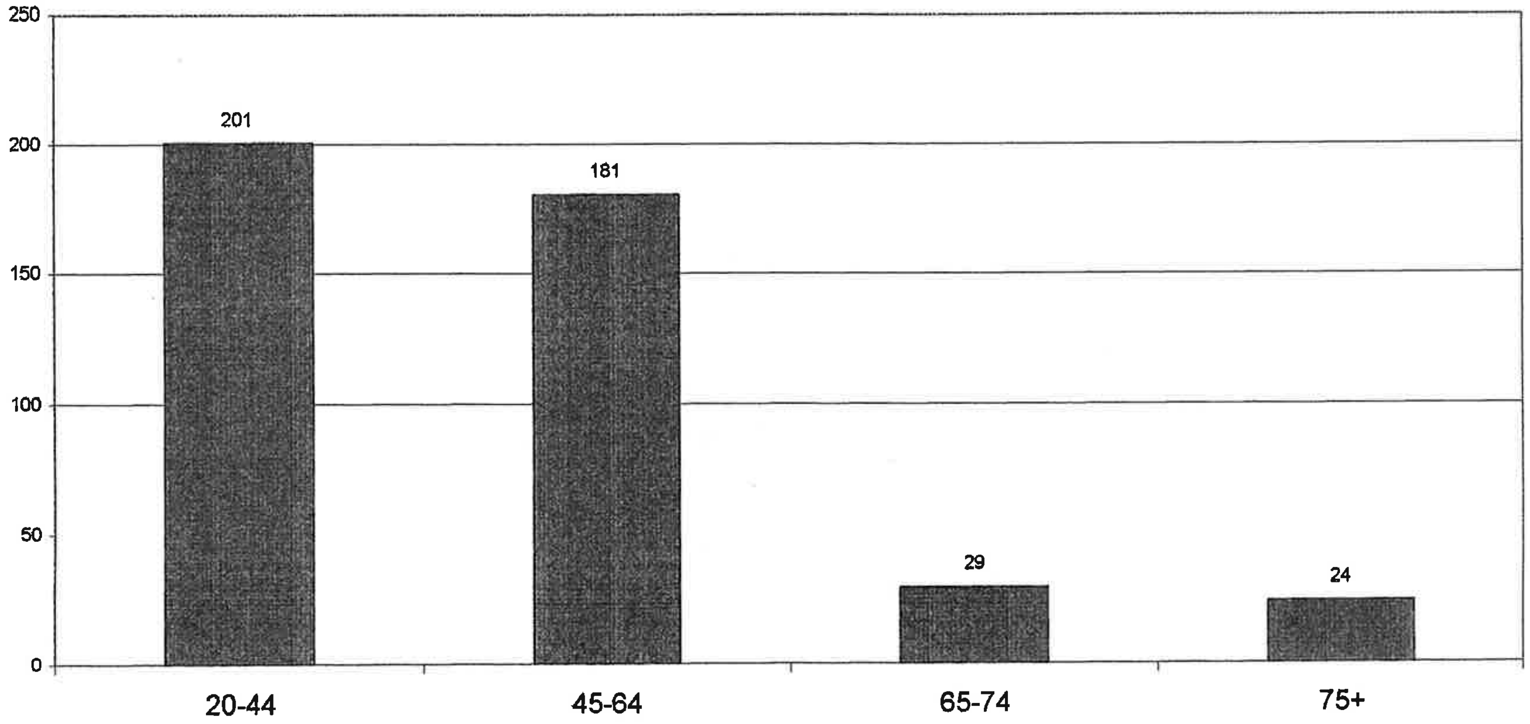
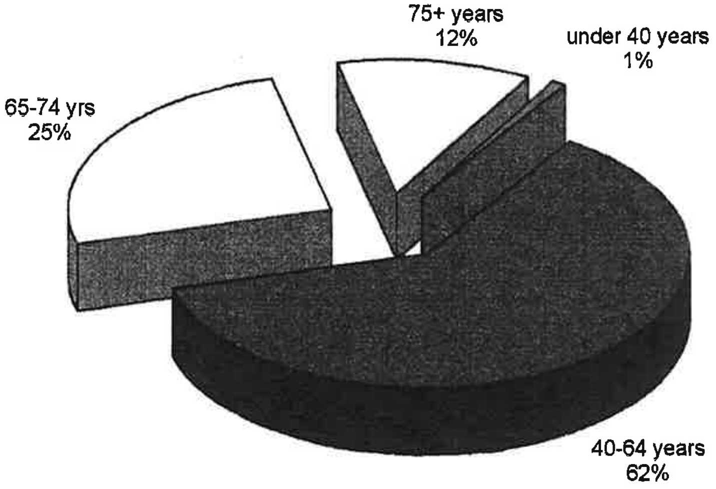


Figure 3: The number of in-patients in long-stay hospitals greater than 366 days (N=435)



Source: McConkey. R., Spollen, M., and Jamison, J. (2003) Administrative Prevalence of Learning Disability in Northern Ireland. Belfast: DHSS&PS.

Figure 4: The number and percentage of primary carers by age bands looking after people with learning disabilities aged 25 years and over in EHSSB area (N=436)



If these figures are projected to the population in Figure 1, this suggests that nearly 500 people live with a carer over 75 years of age and a further 1,000 persons with a carer aged 65 years (NB above the age at which paid carers retire!).

Source: McConkey, R. et al (2003) Future Housing and Support Needs of People with Learning Disability in EHSSB area. Belfast: NIHE/EHSSB