Review of Policy for People with a Learning Disability

DHSS
Department of Health and Social Services

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FOREWORD

Care in the community has been a central tenet of the Government's policy for people with a learning disability for many years now. Throughout, the majority have been cared for in their own homes by their parents and families with varying degrees of support. However, for the significant minority for whom care at home was not possible hospital was the only realistic alternative until the late 1970s.

This report records the development of services for people with a learning disability since then and while it shows that much has been achieved it also clearly indicates that there is still more to do. The report sets the policy direction for the foreseeable future and establishes the core values which should underpin the development of services. Importantly the report points to a number of emerging pressures, which purchasers and providers alike must address if needs are to be met, and aspirations reached.

The vision of the future put forward in the report is one of inclusion; inclusion in society of people with a learning disability and their carers; in decision making; participation so far as is practicable in mainstream education, employment and leisure; and integration in living accommodation and the use of services and facilities not least in the field of health and social services. It is up to us all to include people with a learning disability as we would any member of society and to accept them as they are.

The conclusions and recommendations present both challenges and opportunities. A challenge because of the changes which will be needed in the way we think about people with a learning disability and their needs. A challenge also in using to best effect the knowledge and skills possessed by all who work with people with a learning disability to obtain the best possible value from the resources available.

If we can rise to these challenges, and I believe we can, we will create greater opportunities to develop a more understanding and caring society and to enrich the lives of those we seek to serve.

Malcolm Moss

MALCOLM MOSS
Minister for Health and Social Services

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EXECUTIVE SUMMARY

The Report reviews existing policy and sets the agenda for the development of policy for people with a learning disability into the 21st century.

Scope of the Review

The review of policy for people with a mental handicap was undertaken by a Department of Health and Social Services internal Review Team.
Its remit was:–

(i) to evaluate the development of services since 1978 in the light of existing policy and, in particular, the progress made on implementation of all the key objectives established in the Regional Strategy 1987–92; and

(ii) to establish the core values which underpin the cost effective development of high quality services in the next decade to meet the needs of people with a ***mental handicap*** in all aspects of their lives.

The Review Team recommended that the term mental handicap should be replaced by learning disability.

Methodology

To set a focus for its evaluation, the Review Team identified the basic aims and objectives of the 1978 policy and the associated tasks set in various Departmental publications over the review period. In carrying out its remit it concentrated on those objectives it identified as critical to the two fundamental policy aims:-

- **prevention** which involved education and medical intervention to reduce the incidence or severity of disability; and
- **normalisation** which was seen as a process aimed at achieving integration and the avoidance of labelling rather than segregation.

The Review Team sought, by reference to available evidence and through questionnaire and interview with statutory purchasers and providers, to carry out the evaluation of the policy. It took into account the findings of relevant work and commissioned other work designed specifically to inform the review. In addition to evaluating the policy, the Review Team looked at the effect of wider Departmental policy initiatives and responsibilities of other Government Departments.

A report of the Review Team's evaluation of the 1978 policy was issued in final draft form as a consultative document.

The draft Report contained a section which highlighted key issues identified by the Review Team as affecting the future development of policy, and services to implement the policy, and suggested how these might be addressed. Accordingly, it formed a basis for mapping the way forward for the policy.

The responses to the Review Team's invitation to comment on the draft Report informed the Review Team's deliberations in carrying out the second stage of its task – that is to set core values and determine future policy.

The Report

Section 1 is introductory. It sets out the background to the review, the Review Team's remit and the scope of the review, and the methodology used in carrying out the review.

Section 2 seeks briefly to set the background to the policy. It examines the causes and prevalence of learning disabilities.

Sections 3 to 7 chart the progress made since 1978, and contain the Review Team's findings, in relation to the various elements of the policy:–

- prevention
- hospital services
- care in the community
- related policies
- responsibilities of other Departments

The Team's conclusions are listed at the end of each Section.

Section 8 contains a summary of the evaluation and identifies key issues considered crucial to the development of the policy.

Section 9 looks to the future. It establishes the core values for the effective delivery of high quality services, identifies policy aims appropriate to the end of the 20th century, and addresses the key issues for the policy into the next century.

Section 10 contains some concluding remarks about implementation.

Outcome of the Evaluation

While the absence of data does not allow the effectiveness of the interventionist objectives to be measured **Prevention** of mental handicap remains important. Key issues to be addressed are:-

- targeting health education;
- increasing vaccination uptake rates; and
- developing genetic services.

All the evidence available to the Review Team suggests that **normalisation** has been the right policy. The HHCRU study concludes that community care is preferable to long stay hospital care. Services designed to promote normalisation have in many respects prevented the inclusion of people with a mental handicap in the normal life of the community.

New priorities and pressures are emerging, such as the survival of very profoundly handicapped children and the increased longevity of people with a mental handicap.

Main Pointers to the Way Forward

The needs of clients and carers needs are changing and their aspirations are growing. Many now expect that people with a learning disability should have the same opportunities as all other members of society with regard to education, training for employment and leisure etc. Accordingly, the Review Team recommends that:-

- the aim of Government policy for people with a learning disability should be **inclusion**.

To ensure that this aim is pursued the Review Team recommends that:–

- all agencies contracted to work with people with a learning disability should be required to subscribe to the principles underpinning the policy.

To effectively reduce the incidence of genetic disorder at birth the Review Team recommends that:–

- all potential parents with a family history of genetic or chromosomal disorder should be offered genetic counselling.

The Review Team is of the view that resettlement of those in hospital should be pursued with the utmost vigour as a primary objective. This means that purchasers and providers of support need to ensure that a co-ordinated and responsive service is available in the community. To achieve this objective the Review Team recommends that:–

- Boards need to decide now as to future requirements for hospital provision and, in consultation with all concerned, how a smooth run-down of the existing specialist hospitals can be achieved and alternative, community services and facilities can be put in place;
- specialist hospitals of the future should be smaller, more accessible and less institutionalised than those of today;
- it is essential that proper multi-disciplinary assessment takes place prior to placement and that where placements are made that periodic reviews are undertaken to ensure that the form of care agreed prior to placement remains appropriate;
- every opportunity needs to be taken to plan day services on an outreach basis and to make use of facilities and services available to the general public;
- each HSS trust and DMU needs to consider and determine the role of its community team;
- everyone, whether professional or otherwise, involved in the treatment and care of people with a learning disability should have an appropriate qualification;
- well publicised, imaginative and responsive respite schemes, which are flexible, local, accessible and which are tailored to meet the needs of carers, are required if carers are to continue to be able to sustain their caring role;
- it is essential that GPs and other members of the primary care team are consistently alert to the possible need for specialist services for their patients with a learning disability and their carers.

To overcome financial obstacles to resettlement the Review Team recommends that:–

- each HSS trust and DMU providing services in the community should be given the funding to pay for the specialist hospital needs of their resident populations.

CONCLUSIONS AND RECOMMENDATIONS

General

the expression 'people with a learning disability' should be adopted by the Department (Paragraph 2.2).

multi-disciplinary assessment and regular reviews of individual needs are required (Paragraph 9.6).

Boards must have regard to carers' needs, including training, when developing their purchasing plans, and HSS trusts and DMUs must identify carers' individual requirements for health and personal social services as part of client assessments (Paragraph 9.8).

there is an urgent need for Boards as purchasers, and HSS trusts and DMUs as providers, to identify their data requirements (Paragraph 9.10).

the Department should stipulate its information needs (Paragraph 9.10).

the Department, Boards and HSS trusts should agree common data requirements and definitions (Paragraph 9.10).

in the absence of an official register HSS trusts and DMUs should devise alternative arrangements for collecting, collating and updating basic information (Paragraph 9.11).

needs can only be assessed by an open and full exchange of information (Paragraph 9.11).

the Department should include learning disability in its priority areas for local research taking account, of course, of research conducted elsewhere (Paragraph 9.12).

all agencies contracted to work with people with a learning disability should be required to subscribe to the principles underpinning the policy (Paragraph 9.13).

the quality standards now being set by Boards should provide a better means of assessing quality of life (Paragraph 9.14).

quality standards should be clearly set out, accessible to users and monitored under contract (Paragraph 9.14).

Health Promotion

Health Education

a higher profile should be given in health education to the risks of learning disability (Paragraph 9.15).

the Health Promotion Agency should examine the merits of a programme, focused at couples at risk of having a baby with a learning disability (Paragraph 9.15).

Genetics Service

the service should continue to be purchased jointly by the Boards and delivered by a single provider (Paragraph 9.19).

an expansion of clinics, on a geographical basis, should provide a more localised and accessible service (Paragraph 9.19).

all potential parents with a family history of genetic or chromosomal disorder should be offered genetic counselling (Paragraph 9.19).

it is essential that professionals counselling couples at risk of conceiving a child with a genetic abnormality are fully informed of the benefits of genetic counselling and of the available services (Paragraph 9.20).

the appointment of sufficient consultancy and support staff is a prerequisite to maximising the potential benefits of the genetics register (Paragraph 9.21).

The Regional Medical Services Consortium should consider the future development of the service (Paragraph 9.22).

Inclusion

the aim of Government policy for people with a learning disability should be inclusion (Paragraph 9.25).

Hospital Services

Reducing the Hospital Population

resettlement of those in hospital should be pursued with the utmost vigour as a primary objective (Paragraph 9.26).

purchasers and providers need to develop longer-term resettlement programmes designed to quicken the pace of discharges with agreed retraction strategies designed to release the funds required to provide the necessary additional community based services (Paragraph 9.26).

community based staff should have full access to hospital in-patients and their records (Paragraph 9.27).

each HSS trust and DMU providing services in the community should be given the funding to pay for the specialist hospital needs of their resident populations (Paragraph 9.28).

specialist hospitals must contract to the minimum level commensurate with the numbers of patients needing assessment and short term treatment which cannot be provided in their permanent home or elsewhere (Paragraph 9.29).

consideration should be given as to whether the current specialist hospital based services and staff should be formally reorganised on a community basis (Paragraph 9.29).

Boards need to decide now as to their future requirements for hospital provision and, in consultation with all concerned, how a smooth run-down of the existing specialist hospitals can be achieved and alternative, community services and facilities can be put in place (Paragraph 9.29).

Improving Hospital Services

specialist hospitals of the future should be smaller, more accessible and less institutional than those of today (Paragraph 9.30).

hospitals should not be used for the provision of respite care (Paragraph 9.30).

the needs of people with a learning disability for general medical treatment and recuperation should be met in the ordinary way in a general hospital (Paragraph 9.31).

Boards and HSS trusts must take steps to address emerging pressures to ensure that a new generation of children do not become long-term hospital patients (Paragraph 9.32).

children with a learning disability who require general hospital services should be admitted to paediatric departments (Paragraph 9.33).

every effort needs to be made to ensure that hospital accommodation, facilities and staffing provided for adolescents are appropriate to their emotional, physical, social, educational and developmental needs (Paragraph 9.33).

Care in the Community

General

purchasers and providers of support need to ensure that a co-ordinated and responsive service is available to meet identified need. (Paragraph 9.34)

Residential and Nursing Home Services

there is a need for the retention of a minimum level of statutory services (Paragraph 9.36).

intangibles such as the mix of clients, the staff mix and regime, and the pattern of the residents' day, can be more important to quality of life than the overall number of places in a home (Paragraph 9.37).

it is for purchasers, taking appropriate advice, to decide on the range and size of the residential and nursing home provision that they wish to purchase having regard to the inclusion policy aim and the assessed needs of individual clients (Paragraph 9.38).

it is essential that proper multi-disciplinary assessment takes place prior to placement and that where placements are made that periodic reviews are undertaken to ensure that the form of care agreed prior to placement remains appropriate (Paragraph 9.39).

all settings should be encouraged to implement approaches to care designed to further development of skills and autonomy (Paragraph 9.40).

Boards need to consider whether the placements arranged for discharged patients remain the most appropriate in developing skills and autonomy (Paragraph 9.40).

Day Services

people with a learning disability who can benefit from further education or training for employment should be directed to the appropriate statutory body and should be entitled to expect the same opportunities as all other members of society (Paragraph 9.43).

trainees and carers must be made aware of the commitment being expected of them when training for employment is proposed and make that commitment before training commences (Paragraph 9.44).

every opportunity needs to be taken to plan day services on an outreach basis and to make use of facilities and services available to the general public (Paragraph 9.45).

it is essential that Boards and HSS trusts should seek ways to reduce the pressure on statutory day care places. They should encourage input from the independent sector and involve other agencies, such as the Arts Council, the Sports Council, District Councils and youth and community groups, in providing a choice of day activities appropriate to assessed needs (Paragraph 9.46).

Multi-disciplinary Community Teams

each HSS trust and DMU needs to consider and determine the role of its community team, its leadership, composition and management to ensure the provision of a co-ordinated, quality service, and publicise how it can be accessed (Paragraph 9.47).

for people with a learning disability it is particularly important that their needs for therapeutic services be taken fully into account (Paragraph 9.47).

service providers also need to examine the relationship and lines of communication which are needed between multi-disciplinary community teams, specialist services, GPs and primary health care teams (Paragraph 9.48).

Specialist Support Services
specialist peripatetic community intervention teams should be deployed to work in partnership with primary health care teams (Paragraph 9.49).

Staff Education, Training and Development
everyone, whether professional or otherwise, involved in the treatment and care of people with a learning disability should have an appropriate qualification (Paragraph 9.51).

opportunities for cross professional training should be explored and exploited (Paragraph 9.52).

hospital staff who have not had experience of working in the community should be given appropriate preparation for that role (Paragraph 9.52).

relevant courses should be included under the post graduate training allowance scheme for GPs (Paragraph 9.53).

Respite Care
well publicised, imaginative and responsive respite schemes, which are flexible, local, accessible and which are tailored to meet the needs of carers, are required if carers are to be able to sustain their caring role (Paragraph 9.55).

the continued use of hospital beds for respite purposes is not appropriate (Paragraph 9.55).

Related Policies

it is essential that GPs and other members of the primary care team are constantly alert to the possible need for specialist services for their patients with a learning disability and their carers (Paragraph 9.58).

GPs and other members of the primary care team should adopt a pro-active approach to ensure that the general health, and indeed other needs, of people with a learning disability are detected (Paragraph 9.58).

Inter-Agency Co-operation

good liaison arrangements between all of the agencies involved are necessary both at the strategic planning level and at the point of service delivery to ensure the development and implementation of compatible and co-ordinated strategies (Paragraph 9.61).

the remit of the Departmental Policy Forum on Disability established under the auspices of the Social Steering Group to co-ordinate disability policy and its presentation in Northern Ireland should be extended (Paragraph 9.62).

SECTION 1 – INTRODUCTION

Scope of the Review

1.1 The Department's policy for people with a mental handicap was last set out in 'Services for the Mentally Handicapped in Northern Ireland – Policy and Objectives' (the 1978 Statement) which was published in 1978. It is therefore 15 years, and in many cases longer, since the various elements of the policy were first promulgated.

1.2 Although the broad aims and objectives of the 1978 Statement and many of the principles which underpinned them still pertain, the pace, and to some degree the pattern, of development of the services envisaged in that document to achieve the objectives have been overtaken by events. Not least of these were the Mental Health (Northern Ireland) Order 1986 which effectively replaced the Mental Health Act (Northern Ireland) 1961; the Education and Libraries (Northern Ireland) Order 1986 under which responsibility for the education of people with a mental handicap transferred from the Department to the Department of Education; and the Disabled Persons (Northern Ireland) Act 1989.

1.3 Some of the objectives set in 1978 were subsequently developed or refocused – notably in 'You & Your Baby', the Report of the Advisory Committee chaired by Dr T T Baird on Infant Mortality and Handicap in Northern Ireland (the Baird Report) published in 1980 and the Department's Regional Strategies for the Northern Ireland Health & Personal Social Services 1987–92 and 1992–97 (the Regional Strategies) which prioritised objectives and set intermediate targets.

1.4 The Department's policy paper 'People First', which was published in 1990, set out the broad framework for the development of community care services in Northern Ireland for vulnerable people in the 1990s. The division of purchaser and provider roles within the health and personal social services and the establishment of HSS trusts have created opportunities for the development of the diversity of service provision envisaged in 'People First'.

1.5 More recently the Department has focused on targeting health and social need and quality of care as important dimensions in the assessment of need and service planning and delivery.

1.6 The Department decided, therefore, that a comprehensive review was necessary. The internal Review Team was established with the following terms of reference:–

(i) to evaluate the development of services since 1978 in the light of existing policy and, in particular, the progress made on implementation of all the key objectives established in the Regional Strategy 1987–92; and

(ii) to establish the core values which underpin the cost effective development of high quality services in the next decade to meet the needs of people with a mental handicap in all aspects of their lives.

The membership of the Review Team is set out in Annex 1.

1.7 In addition to the policy for health and personal social services, which is the responsibility of the Department, other aspects of Government policy – housing, education, employment and leisure – which have an important impact on the quality of life of people with a mental handicap, but are the responsibility of other Departments, were included within the general scope of the review.

Background

1.8 Prior to 1973 services for people with a mental handicap were administered by 3 Special Care Management Committees on behalf of the Northern Ireland Hospitals Authority. Hospital consultant psychiatrists were responsible for managing all the special care services including schools, day centres and, where they existed, residential homes in the community. The 1973 reorganisation afforded the opportunity to retain the advantages of a unified approach while integrating the services into the general health and personal social services structures. Traces of the pre-1973 special care approach persisted in 1978 and were reflected in the 1978 Statement. At the same time the Statement reiterated the advantages of integration of the management arrangements for services for people with a mental handicap with those for others. Although management arrangements for the delivery of services by Boards have changed several times since 1978, integration has been achieved.

1.9 The number of people with a mental handicap in Northern Ireland has never been established precisely – nor was it considered necessary to do so. The Department has routinely collected information on the number of people in contact with social services staff but this can at best be regarded as a proxy measurement. In 1978 some 5,709 people with a mental handicap were in contact with social services staff. This number has increased steadily over the years to 6,751 in 1992 – the latest year for which figures were available to the Review Team.

1.10 The 1978 Statement identified two fundamental policy aims. The first – **prevention** – involves education and medical intervention to reduce the incidence or severity of mental handicap. The second aim – **normalisation** – was seen as a process aimed at achieving integration and the avoidance of labelling rather than segregation.

1.11 In outlining its views on the principal elements of prevention in the 1978 Statement the Department cited the improvement of health education; the development of programmes of preventative medicine such as vaccination, and genetic counselling and screening; improving antenatal and perinatal services; and upgrading child health services. At the same time it mentioned wider societal needs such as improving social and environmental conditions and reducing the incidence of poverty.

1.12 In the context of the second policy aim, the 1978 Statement described normalisation as assisting people with a mental handicap to attain the maximum development consistent with their degree of disability and to share for as long as possible and as far as may be in the life of the community. Care and facilities should be matched to their needs; options for each individual should be kept open for as long as possible; and no one should have to remain in unsuitable accommodation simply for lack of a better alternative.

1.13 Linked to normalisation, integration was seen to mean that no one with a mental handicap should be excluded from society, deprived of membership of the wider community or institutionalised for want of stimulation or for lack of suitable facilities for care and treatment.

Methodology

1.14 To provide the Review Team with some focus for the review, work was put in hand to identify the main objectives set out in the 1978 Statement together with various associated sub-objectives, tasks and targets set therein and in later Departmental publications. The breakdown is summarised in Annex 2. The sub-objectives and their associated tasks and targets were attributed to particular objectives for the purposes of evaluation although their interrelationship is recognised. This is discussed in Section 8 of the Report.

1.15 Its remit committed the Review Team to carry out an evaluation of the health and social services developed since 1978 to meet each policy aim. The Team decided that it would best meet its remit by concentrating on those Departmental objectives identified as critical to the prevention specifically of mental handicap and to the normalisation process. Some objectives reflect wider Departmental policy initiatives which impact on the whole population and were not specifically included in the evaluation. Others are the responsibility of other Departments, but as already indicated, the Review Team looked at their impact on the lives of people with a mental handicap.

1.16 The policy applies to the care and treatment of all people with a mental handicap. Consequently there was no scope to carry out a comparative analysis with a control group and so the policy was evaluated by its effect on the whole client group.

1.17 At the outset the Review Team decided that it was fundamental to the review to obtain as accurate a picture as possible of current service provision to supplement the data routinely collected by the Department, and to have a reasonably accurate estimate of the numbers of people for whom services may at some time be required. Accordingly, a survey was carried out to gather base data on service provision and assessed need from Units of Management providing community services. The Review Team asked each Unit, among other things, to quantify the number of people with a mental handicap known to it as opposed to the number in contact with social services staff. The figures returned totalled 8,200 – a breakdown by location and Board is shown in Table 1.

1.18 The Review Team sought, through a series of interviews with representatives of the Boards at Area level as purchasers and their Units of Management (some of which are now HSS trusts) as providers, to identify the issues which were affecting the continued implementation of policy. Discussions were also held with staff in the Health Promotion Agency, the Department of the Environment, the Health and Safety Inspectorate, the Department of Education, and the Training and Employment Agency on issues which impacted on areas of service delivery for which they have a direct responsibility.

1.19 The Review Team took into account relevant work undertaken by the Boards and other agencies and commissioned other work specifically for the Review. Details are listed in Annex 3.

1.20 The 1978 Statement listed, in its Appendix II, the main principles which underpinned the policy and objectives for service development set out in the Statement. These principles were drawn from the 1971 White Paper 'Better Services for the Mentally Handicapped' and are reproduced in Annex 5. The Review Team considered their relevance today in establishing core values underpinning the future cost effective development of high quality services.

1.21 Policy evaluation guidance recommends that, rather than a simple comparison with the case obtaining prior to the implementation of the policy, a truer assessment can be seen from a comparison with what might have occurred, had it not been implemented. This involves judgments, based on the observable trends and known external influences, which would have affected the outcomes, even if no changed intervention had taken place. The Review Team has taken this approach where appropriate in relation to certain specified elements of policy.

1.22 A Report of the Review Team's evaluation, that is the outcome of the first part of its remit, was issued in final draft form as a consultative document. The draft Report contained a section which set out a number of issues for the future identified by the Review Team in the course of its evaluation and tentatively suggested how these issues might be addressed. Comments were invited from a wide spectrum of interested parties including caring organisations in the statutory, voluntary and private sectors. Very helpful and informative comments were received from the respondents listed in Annex 4. These comments were all considered by the Review Team and many are reflected in this, the Review Team's definitive Report.

The Report

1.23 Formal policy evaluation must examine aspects of policy in a structured way and the format of the Report necessarily reflects that approach. Equally the Review Team was keen that the Report should be written with a general readership in mind and hence where possible the use of much of the jargon associated with policy evaluations has been avoided.

1.24 Sections 2 to 8 are in many ways retrospective insofar as they reflect the Review Team's evaluation findings and conclusions. Section 2 examines the causes and prevalence of mental handicap. Following sections summarise the findings of the Review Team's evaluation. **Prevention** measures are examined in Section 3. Sections 4 to 6 chart the progress made since 1978 in achieving the targets for **normalisation** set out in the 1978 Statement and in the 1987–1992 Regional Strategy – primarily for hospital, residential, day care, and ancillary services usually delivered as a specific care programme. Other arrangements designed to promote normalisation are also discussed. Responsibilities of other Departments are described in Section 7. Section 8 contains an overview of the outcome of the steps taken by the Department and Boards to implement the policy and sets out the key issues identified by the Review Team as affecting policy implementation, now and anticipated in the near future, and which must be addressed by service planners in pursuit of the policy objectives.

1.25 Section 9 outlines the Review Team's vision for the future. It seeks to establish the core values on which policy objectives for the future should be based. It also examines the key issues set out in Section 8 and makes recommendations as to how the policy objectives should be pursued to the end of this century and beyond.

1.26 The final section stresses the changing patterns of need experienced by people with a mental handicap and the consequent need for policy responses and service development. It does not address in specific detail the full range of services required in the years to come. This was not part of the Review Team's remit. Nevertheless, the Review Team hopes that Government Departments and their Agencies will take its findings and recommendations fully into account in translating policy into service provision.

SECTION 2 – IDENTIFICATION, CAUSES AND PREVALENCE

Definition

2.1 As a first step the Review Team decided it would be useful to define its target population. The term 'mental handicap' which has been used to identify that population is defined in the Mental Health (Northern Ireland) Order 1986. It is defined there as 'a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning'. The condition is permanent though in many cases much can be done to lessen its impact on the quality of an individual's life.

2.2 Although the term 'mental handicap' is still used by some, many people regard it as demeaning while others simply do not like it. Alternatives in use include learning difficulty, intellectual impairment and intellectual disability, but 'learning disability' is generally accepted as the most meaningful term to cover the wide variation in ability and associated needs of the people concerned. It was the term most favoured by those who commented on the issue to the Review Team. Consequently, although the Report refers to 'people with a mental handicap' for the purposes of the review of existing policy, the expression 'people with a learning disability' is introduced in Section 9. The Review Team recommends that **the expression 'people with a learning disability' should be adopted by the Department.**

2.3 Mental handicap is often analysed by level of severity measured by intelligence quotient (IQ) ranging from mild (IQ between 50 and 70) through moderate and severe to profound (IQ less than 20). Those with an IQ just higher than 70 do not normally fall within the definition. However, IQ tests alone cannot give a wholly accurate representation of a person's ability. Equally important are concurrent deficits or impairments in adaptive functioning such as social skills and responsibility, communication, daily living skills, personal independence, and self sufficiency. These can also vary to significant degrees.

2.4 People with a mental handicap may frequently also have physical or sensory impairments. Some suffer from mental illness or display behavioural problems. A number exhibit autistic features.

2.5 A number of those who commented on the draft report mentioned problems, when assessing individual abilities (and having regard to the definition of 'mental handicap' in the Mental Health (Northern Ireland) Order 1986), in deciding whether a particular individual should be diagnosed as a person with a mental handicap and if so how to classify the severity of that disability. It was suggested that the Review Team should offer guidance to practitioners. Whilst recognising the difficulties and the long term consequences which can stem from a diagnosis for data collection, service planning and development, and not least in access to services for those on the borderline, the Review Team was of the view that it did not lie within its remit to be prescriptive in this area. The interpretation of legal definitions is ultimately a matter for determination by the Courts. Furthermore, the widely varying needs of people with a mental handicap demand very individual assessments and are, therefore, matters for clinical judgment. It is too simplistic to think of them as forming a single homogeneous client group.

Causes

2.6 In a high percentage of cases of severe or moderate mental handicap causal factors can be identified. Chromosomal disorders, predominately Down's Syndrome and Fragile X Syndrome, are the most common. Single gene disorders, of which over 2000 have been identified, account for a significant proportion. Congenital infection such as rubella in the first eight to ten weeks of pregnancy results in foetal damage in up to 90% of cases and multiple defects including mental handicap are common. Other causal factors may include abnormalities of the central nervous system such as spina bifida and hydrocephalus. Metabolic disorders such as phenylketonuria and hypothyroidism may lead to damage to the central nervous system and thus to severe mental handicap. Many viral and bacterial infections, such as measles, mumps, meningococcus and haemophilus influenzae type b (Hib), can cause meningitis or encephalitis in young children leading to permanent neurological damage including intellectual impairment. Low birthweight, premature birth, adverse perinatal circumstances, and foetal exposure to toxins may be contributory factors.

2.7 In most cases of mild mental handicap causes cannot be identified with certainty though environmental factors appear to be important. The association between social deprivation and mental handicap has long been known. Since 1978 there has been an increasing recognition of the effect of inadequate nutrition in pregnancy and young children, the dangers of alcohol consumption and smoking during pregnancy, the growing problem of drug abuse and HIV infection, and of other environmental hazards such as lead or carbon monoxide poisoning. Domestic violence and child abuse can also be contributory factors. Genetic factors are identified in comparatively few cases.

Prevalence

2.8 In common with the rest of the United Kingdom, little data exist on the prevalence of mental handicap in Northern Ireland. Also, there are no data available on the severity of mental handicap nor is there a reliable incidence rate.

2.9 Figures routinely collected by the Department record the numbers of people with a mental handicap in hospital, or in touch with social services departments. These can be used for activity analyses but are not reliable proxies for measuring prevalence since some people probably appear in both figures each year and an equally indeterminate number are neither in hospital or in touch with the social services in any given year. Indeed, the Review Team found that in 1992 of the 8,200 people with a mental handicap known to the Units of Management only 6,751 had been in contact with the social services during that year. Also, whilst showing a general upward trend, the numbers in contact fluctuate from year to year and cannot therefore be used to help to establish prevalence.

2.10 Analyses, by Board area, of the total number of people with a mental handicap in contact with the social services in 1992 suggests a west to east gradient with a significant variation between the Boards. However, analyses of the total number of known people with a mental handicap, also by Board area, suggests that there is no significant geographical variation in prevalence as Table 1 indicates.

Identifying the Population

2.11 In 1978 a district register was maintained by Boards as part of the formal statutory ascertainment of people with a mental handicap required by the Mental Health Act (Northern Ireland) 1961. The register was seen as a possible basis for service planning. Although the requirements for notification and assessment were repealed by the Mental

Health (Northern Ireland) Order 1986 the Department, at the time, asked Boards to continue to maintain registers containing, at least, the minimum data commensurate with the service needs of individuals and their own planning requirements.

2.12 The Review Team found that few Units of Management maintained a 'register' capable of providing planning information. Although each Unit had access to information on the number of people with a mental handicap known to it and living within its area this was generally held on various 'lists' maintained by discrete services and different professionals within each Unit rather than on common files or in common records. Even where a Unit's records were computerised, sufficient information was not readily available for assessment and planning purposes on individual or on overall levels of need.

2.13 In discussion with the Review Team, Boards were acutely aware of their lack of precise information about the level of overall need in their areas. They recognised also that they were dependent on their Units of Management, the providers of services, to advise them of that need, of how that need should be measured and how it should be met. Clearly providers will always be the Boards' main source of information. However, as purchasers the Boards must identify their data requirements.

2.14 The total of 8,200 people already referred to in paragraph 1.17 is the most up to date information available to the Review Team. It is not, however, possible to be specific about the nature of their needs in the absence of analytical information about their varying degrees of handicap. What is clear is that priority needs are continuing to change. There is evidence of an emergence of a new group of babies, especially those with a low birth weight, born with profound mental handicap who through medical intervention are surviving into childhood and perhaps beyond. The needs of this group will have a fundamental effect on their families and the services available. At the same time, the increased longevity enjoyed by the general population extends to people with a mental handicap. Indeed, research has shown that the increase in their life expectancy is even more pronounced. Here again the effects will be felt by families and service purchasers and providers.

Conclusions

- the term 'learning disability' is more widely acceptable than 'mental handicap'.

This section raises two key issues which the Report will return to later. These are:–

- purchasers and providers need to determine information requirements for needs assessment and service planning, delivery and evaluation; and
- priority needs are continuing to change.

SECTION 3 – PREVENTION

Intervention

3.1 The incidence, and severity, of mental handicap can be reduced by primary, secondary and tertiary interventions. Broadly speaking primary intervention takes place prior to conception (and during childhood) and includes health education, vaccination programmes, genetic counselling for families at high risk of carrying genetic disease, and contraceptive advice. Secondary intervention follows conception and involves counselling, and identification of an affected foetus by screening and diagnosis to enable parents to make an informed choice about the outcome of the pregnancy. Tertiary intervention follows birth and involves screening, diagnosis and treatment of conditions which can cause mental handicap. Examples include thyroid replacement therapy in cases of hypothyroidism, and a phenylalanine free diet in the treatment of phenylketonuria. Recognition of the individual potential of people with a mental handicap and early intervention to maximise that potential can minimise handicap and reduce dependency throughout life. Voluntary organisations can play a significant role in supporting and encouraging new carers.

3.2 The 1978 Statement stressed the vital importance of education and preventive medicine. The improvement of health education, and the development of vaccination and of genetic counselling and screening programmes, were cited as measures which were the responsibility of the Boards along with improving antenatal and perinatal services and upgrading child health services.

3.3 No specific tasks or targets were set in the 1978 Statement but the Baird Report contained a number of recommendations on prevention of mental handicap. As no additional resources were available at that time Boards were asked to concentrate on the recommendations with minimal or no cost implications. It was recognised that further progress would depend mainly on the reallocation or redeployment of existing resources rather than on the investment of new money for which there would be competing demands.

Health Promotion and Education

3.4 Health education, including the education of professionals, has advanced considerably since 1978. Each Board has a health promotion unit. In recognition of the need to increase public awareness of issues affecting health, to prevent illness and to avoid handicap, in 1988 the Department formed a Health Promotion Unit, which was established as an independent Agency in 1990.

3.5 The Health Promotion Agency has a wide remit and focuses on issues which have general application such as the harmful effects of smoking and alcohol consumption, and the benefits of exercise and a healthy diet. However, specific advice on the prevention of mental handicap (with the possible exception of vaccination campaigns) has not enjoyed as high a profile as other issues. Nevertheless, the Pregnancy Book published by the Health Promotion Agency contains general information on the detection of abnormalities.

3.6 In 1991 the results of the Medical Research Council Vitamin Study of folic acid and other vitamin supplementation in the prevention of neural tube defects were published. An Expert Advisory Group, convened to consider the dietary implications of the Study, recommended that all women planning pregnancies should supplement their dietary folic acid intake. This advice was disseminated to all professionals, the Health Promotion Agency has updated its publications to include the guidance, and posters and complementary leaflets have been widely distributed throughout the health service. It is anticipated that these measures will reduce the incidence of neural tube defects in newborn babies.

3.7 In 1980 the Baird Report recorded that 'many parents at risk of having abnormal offspring are not aware of the existing genetic advisory service and some health and social services staff need to improve their knowledge of it'. It contained a recommendation that a booklet on the facilities of the service should be produced for all relevant staff and for voluntary bodies working in the field. The findings of the Review Team suggest that little seems to have changed for the better in the intervening period. At the same time the potential benefits to the population of genetic services have increased since 1980 because it is now possible to identify carriers of many genetic disorders and to make a diagnosis before birth.

Vaccination

3.8 Routine childhood immunisation has always been an important weapon in the fight to eradicate communicable diseases which, as explained in paragraph 2.6, can lead to mental handicap. The 1987–1992 Regional Strategy identified immunisation as a vital component of the prevention strategy. It set a 1992 target to ensure that at least 90% of children were immunised against measles and 95% of girls were immunised against rubella by their 14th birthday.

3.9 Uptake rates for immunisations have improved steadily since 1978. The percentage uptake rate for measles was only 5.1% in 1978. By 1987 uptake had risen to 55.6%. By 1988, the last year for which separate figures for vaccination against measles are available, uptake was 79%. The percentage uptake rate for immunisation against rubella was only 54.8% in 1979. Uptake had risen to 88.4% by 1987 and increased further to 97.8% by 1990.

3.10 A combined vaccine against measles, mumps and rubella (MMR) was introduced in October 1988 and is offered to all children. Uptake for the year ended 31 March 1990, the first full year of the MMR programme, was 87.4%. Since 1990 MMR vaccination has been part of general practitioners' targets for childhood immunisations. The uptake rate had risen to 94.1% by 1991 and is on course to meet a regional target rate of 95% by 1997. However, there are significant variations in MMR uptake rates – between 91% and 97% – at Board level. Rubella immunisation of twelve and thirteen year old girls and non-immune women is continuing.

3.11 At the beginning of October 1992, a new vaccine against Hib, an important cause of meningitis in children, was added to the primary immunisations given to babies. A catch up programme for children aged up to four years was also put in place.

3.12 The effectiveness of immunisation is difficult to measure precisely against changing underlying factors. For example, the chances of contact with disease increase in epidemic years. Nevertheless, it is possible to track the incidence over time of notifiable diseases. In 1978 five cases of rubella affected babies were confirmed. In 1979, an epidemic year, 11 cases were confirmed. In 1983 and 1984, also epidemic years, respectively only three and four cases were confirmed. None were recorded throughout the 1987 to 1992 strategic period. Prior to the introduction of the Hib vaccine, each year about 1 in 600 children under five years of age developed some form of the disease. There is already evidence that by 1993 this had been dramatically reduced by the introduction of the vaccine.

Genetic Services

Counselling

3.13 Genetic counselling provides information and advice mainly to parents and potential parents at risk of bearing children affected by genetic disorders.

3.14 The Baird Report recommended that the organisation of the genetic counselling service should be retained on a regional basis, that the service should be expanded and that a genetic register should be developed.

3.15 A regional genetic counselling service is provided by the Belfast City Hospital Trust and is currently purchased jointly as a specialised service by the Boards through the Regional Medical Services Consortium.

3.16 The Baird Report recommended an increase in the number (6.5) of clinical consultant geneticist sessions available in Northern Ireland and for the necessary ancillary staff to be made available. In acknowledgement of the need to expand the service, the Report contained a recommendation that a senior registrar post should be established. Whilst this post was duly established an additional consultant post has not been created. A report published by the Clinical Genetics Committee of the Royal College of Physicians in October 1991 indicated that a ratio of 2 clinical consultant geneticists per 1m population is required. In Northern Ireland this would translate as 3 full-time posts, with the appropriate junior and other medical and clinical support staff. At present Northern Ireland is served, as in 1980, by 1 joint appointment consultant (half a full-time post).

3.17 Genetic counselling clinics have been established at Belfast City Hospital – 169 per year, the Royal Belfast Hospital for Sick Children – 72 per year, the Ulster Hospital – 9 per year and at Altnagelvin Hospital – 19 per year. Although the service is available to all Northern Ireland residents the locations for service delivery are heavily biased within the Eastern Board. The number of patients attending genetic counselling and diagnostic clinics is, however, reflective of the overall population of each Board. In the year ended 31 March 1993 of some 2,396 patients attending 44% were from the Eastern Board, 21% from the Northern Board, 15% from the Southern Board and 17% from the Western Board.

3.18 Steps have been taken to establish a comprehensive genetics register for the express purpose of tracing, following up and counselling individuals who are at high risk (greater than 1 in 10) of transmitting a serious genetic disorder to their offspring. The necessary computer hardware has been provided and the databases have been compiled but efficient and effective use of the register is being hindered by the lack of support staff.

Screening and Diagnosis

3.19 The Baird Report also contained recommendations on the screening and antenatal diagnosis of pregnancies at risk of neural tube defects and chromosomal abnormalities. An extremely high incidence (4.1 per 1,000 births in 1980) of open neural tube defects in Northern Ireland was an important factor behind a recommendation that urgent consideration should be given to introducing a voluntary ('opting in') antenatal serum alphafetoprotein (AFP) screening programme. An expert advisory group, convened in

1989 to review the service, concluded that the 'present arrangements for prenatal screening were unsatisfactory and unevenly spread across the Province and did not meet the expectations of many patients'. In 1990 the Department's Chief Medical Officer advised the Boards' Directors of Public Health that the AFP screening programme for neural tube defects should be established on an 'opt-in' basis for all mothers. To date universal screening is not offered.

3.20 Nevertheless, there has been a rapid decline in the incidence of neural tube defects, from 2.2 per 1,000 births in 1984 to 0.9 per 1,000 births in 1992. The reasons for this decline are not fully understood but some reduction in incidence can be attributed to the multivitamin dietary supplementation for mothers with a previous history of neural tube defect. Despite the decline, at present the prevalence in Northern Ireland remains higher than that of the United Kingdom average.

3.21 Biochemical screening (for example AFP or more recently the triple test) can indicate a serious possibility of Down's Syndrome. Antenatal diagnosis following screening may be confirmed by amniocentesis and cytogenetic examination. Other antenatal factors such as maternal age, foetal growth retardation and hydramnios can also indicate the need for amniocentesis and subsequent cytogenetic diagnosis of other chromosomal abnormalities including Down's Syndrome.

3.22 Whilst the value of AFP screening in identifying the risk of Down's Syndrome has been recognised, the extent of prenatal screening for Down's Syndrome is left to the discretion of individual obstetricians. To date antenatal screening in Northern Ireland is targeted only at mothers with a previous neural tube defect or mothers over 35 years. The incidence of Down's Syndrome in Northern Ireland was 1.1 cases per 1,000 total births in 1992 – higher than the United Kingdom average – and is now higher than the rate for neural tube defects.

3.23 Each year severe mental handicap is prevented in five or six children with phenylketonuria by special diet. In 1980, on the advice of the Advisory Committee chaired by Dr T T Baird, neo-natal screening of all newborn babies for phenylketonuria was extended to provide screening for congenital hypothyroidism. Now all babies are so screened and each year profound mental handicap due to hypothyroidism is prevented in about 10 children by thyroid replacement therapy.

3.24 In the absence of prevalence rates, the Review Team was unable to carry out an evaluation of the service to date or to test the extent to which the existing counselling clinics and screening and diagnostic testing are meeting need.

Diagnostic Laboratory Services

3.25 Investigations including cytogenetic analysis of blood, bone marrow, skin tissue, and amniotic fluid cells are an integral part of genetic counselling and screening. In keeping with its proposals for an expanded genetic service the Baird Report contained recommendations for the provision of the necessary staff, facilities and equipment to expand the service to meet known need. Staff have been recruited, equipment has been supplied and modern laboratory facilities have been provided in the Belfast City Hospital. The overall level of diagnostic work has increased commensurately. For example, the number of chromosome analyses on peripheral blood samples increased from 750 in 1986 to 1161 in the year ended 31 March 1993, and on amniotic cells from women at risk from 426 to 635 over the same period.

3.26 Since 1980 molecular diagnosis has become an increasingly important laboratory facility in clinical diagnosis. A laboratory was established in 1989 with special Departmental funding to develop molecular diagnosis for cystic fibrosis, muscular dystrophy and Huntington's disease. In that year tests were carried out on 678 samples; by the year ended 31 March 1993 the total had increased to 1,201.

Maternal and Child Health Services

3.27 The Baird Report contained a number of specific recommendations for the development and improvement of antenatal, perinatal, neonatal and postnatal care. The 1987-1992 Regional Strategy set as an objective the development of continuous child health surveillance particularly multidisciplinary developmental screening to improve the early detection and treatment of physical and mental handicap. As maternal and child health services have improved so have survival rates of very small and premature babies. Perinatal mortality fell from 18.1 per 1,000 total deliveries in 1978 to 8.3 in 1992; neonatal mortality fell from 10.5 per 1,000 live births to 4.1; and postnatal mortality fell from 5.4 to 1.9. Over the same period infant mortality fell from 15.9 to 6.0. These reductions have been aided by an increasing sophistication of equipment and treatment techniques. However, throughout the review period there have been marked variations of mortality rates at Board and local levels.

Conclusions

- health promotion and education directed specifically at preventing mental handicap has not had a high profile over the review period.
- improving vaccination uptake rates are reflected in a reduction in incidence of communicable disease associated with mental handicap.
- there are significant variations in vaccination uptake rates but Boards are on schedule to meet the target set in the 1992-1997 Regional Strategy.
- there have been considerable improvements in the genetic counselling and screening services.
- the genetic service is primarily Belfast based although the number of patients attending clinics is in proportion to each Board's population.
- there are deficiencies in the screening service.
- full implementation of the recommendations in the Baird Report has been hindered by a lack of adequate funding.
- the pace of developments in genetics since 1980 means that many of the recommendations in the Baird Report are now outdated and, despite the provision of a satisfactory genetics service being a critical issue in the 1992–1997 Regional Strategy, Northern Ireland is falling behind.

With the increasingly rapid development of genetic medicine the possibilities for preventing and reducing the severity of mental handicap are considerable. This key issue is examined in Section 9 of the Report.

SECTION 4 – HOSPITAL SERVICES

Reducing the Hospital Population

4.1 The majority of people with a mental handicap in Northern Ireland have always been cared for at home with varying degrees of support. Few alternatives to hospital care were available in 1978 where, for whatever reason, home care was not an option. For that significant minority continuing long-term care in a mental handicap hospital, or in a psychiatric hospital, was the only realistic alternative.

4.2 On 31 December 1978 there were 1,337 patients in mental handicap hospitals and 362 patients with a mental handicap in psychiatric hospitals. The 1978 Statement identified a reduction in the numbers of hospital in-patients as an objective to be achieved but did not set a specific target. By 31 December 1986 the numbers in hospital had fallen to 1,289 and 216 respectively. The relatively small reduction in in-patient numbers between 1978 and 1986 may be attributed to the slow growth of residential places and day care facilities described elsewhere in this report.

4.3 A target reduction of at least 20% was set in the 1987–1992 Regional Strategy. Accordingly, each mental handicap hospital developed a pro-active rehabilitation programme – Muckamore Abbey Hospital has 32 rehabilitation places, Longstone Hospital has 31 and Stradreagh Hospital has 6 places. Progress in achieving the objective is depicted graphically in Table 2. Within the general target the Department placed particular emphasis on a reduction in the numbers of people with a mental handicap in psychiatric hospitals, and on reducing to the absolute minimum the numbers of mentally handicapped children in hospital.

4.4 Rehabilitation programmes developed by the hospitals were designed to actively assist the resettlement process. However, the evidence available through the HHCRU Study suggests that on balance resettlement programmes have focused primarily on preparing people for, and organising their care, in the community rather than attempting to raise their level of functioning and so reducing dependency before leaving hospital. In any event, as the HHCRU Study found, a high proportion (73% between 1990 and 1992) of patients were discharged to residential or nursing homes.

4.5 To facilitate the general shift in the balance of care from long-stay hospital care to community care for all client groups, the Department has since 1987 allocated bridging finance, totalling £46.9m to the Boards. These funds have been used to expand community services and support, in anticipation of revenue being freed up from the hospital services. A study of how bridging finance has been used has shown that during the 1987–1992 strategic period the funds were spent almost exclusively on mental handicap and mental health programmes of care and were split in almost equal shares between the two.

4.6 The impact of bridging finance is reflected in an acceleration in discharges between 1987 and 1992 over the preceding 8 years as depicted in Table 2. During the 1987–1992 strategic period the number of people in mental handicap hospitals fell by 28% from 1,289 to 926. This compares with an expected 1,182 remaining patients if the 1987 policy had been allowed to continue unenhanced by the impact of bridging finance. The number of long-stay patients fell by 33% from 1,244 to 814. The number of children with a mental handicap in hospital on a long-term basis fell from 31 in 1987 to 8 by the end of 1992. The number of people with a mental handicap in psychiatric hospitals fell from 216 to 121 – a reduction of 44%. This compares with an expected 144 had the policy not been enhanced by bridging finance. The resettled former long-stay hospital patients remain in contact with the health and social services.

4.7 In discussions with the Review Team, the Boards were unanimous in their acclaim of the value of bridging finance. They cited it as a vital factor in enabling them to achieve the target reductions in the numbers of in-patients. Nevertheless, uncertainties in obtaining this funding caused problems to both purchasers and providers in developing their proposals for community care services. To overcome this difficulty the Department decided to consolidate the bridging finance into Boards' baseline allocations. It must also be recorded that bridging finance was not always followed by retraction money. In many cases, Units of Management had to guarantee revenue from their own non-hospital resources before receiving bridging finance.

4.8 Because of a lack of suitable, alternative facilities in the community, the pace of resettlement remains slower than could be achieved. There are still people with a mental handicap being admitted to hospital for assessment or treatment whose admission becomes long-stay. In December 1991 there were 100 people with a mental handicap in hospital whose length of stay was between 1-5 years. That is, they had become long-stay patients during the 1987–1992 strategic period. A further 27 patients had been in hospital for more than 6 months. These admissions swell the ranks of patients waiting to be resettled – 272 at 31 March 1993. Particular difficulties arise in respect of patients requiring semi-secure accommodation or who are detained in accordance with the provisions of the Mental Health (Northern Ireland) Order 1986.

4.9 The reduction in long-stay patient numbers has been accompanied by an increase in the numbers of short term admissions. Admission figures are not collected by the Department but using discharge figures the Review Team concluded that total admissions increased by 100% between 1978 and 1987 and 300% between 1987 and 1992. Units of Management attributed these increases, at least in part, to a lack of community facilities or services capable of providing the intensive medical and nursing care needed by many patients from time to time. There is no evidence to suggest that these episodic admissions are due to any general deterioration in patients' health or behaviour patterns as a result of the community care policy.

4.10 The 1992–1997 Regional Strategy calls for a further reduction in the number of people in mental handicap hospitals from 926 in March 1992 to less than 700 by 1997 and an assurance that by then no child is receiving continuing care in a mental handicap hospital. These objectives are to be achieved through the further development of community facilities. If the pace of reduction over the 1987–1992 strategic period is maintained this target could be achieved well before the end of the strategic period. In the course of 1992/93 the number of places available in the community increased by 200 and the number of long-stay patients in mental handicap hospitals fell by 89. Boards' purchasing plans indicate their intention that the targets for 1997 will be met.

4.11 Prior to April 1993 the resettlement process was undoubtedly aided by the availability of social security benefits payable to people entering independent sector homes. This created a market for independent sector places as the number of patients who could be assisted in this manner was not cash limited. Many placements were arranged by carers without professional advice. Under the community care arrangements effective since April 1993, Boards have the responsibility for the assessment of need and for meeting, from within their own resources, the care costs, hitherto met by social security benefits, of people placed in independent sector residential and nursing homes. Transfers of funds from the social security programme (the Social Security Transfer) are being made to the health and personal social services programme to meet these costs.

Improving Hospital Services

4.12 In 1978 the Department envisaged the recommended reduction in in-patient numbers as an opportunity to provide a better hospital environment, to improve facilities and specialist services, and to move patients to hospitals nearer to their home.

4.13 Hospital facilities have improved substantially since 1978 and overcrowding has been reduced. Local deficiencies in bed numbers have been eliminated. The number of available beds in mental handicap hospitals declined throughout the 1980s as a result of the resettlement process and the development of community facilities. In 1979 there were 1,533 available beds in mental handicap hospitals. This number declined to 1,416 in 1987. During the year from April 1991 to March 1992 there was, on average a total of 1,065 available beds in mental handicap hospitals. The average number of beds occupied during that year was 971.

4.14 Although the number of long-stay patients fell by 33% during the 1987–1992 strategic period the average number of occupied beds fell by only 26% reflecting a retention of beds to meet the increased number of short-term admissions mentioned earlier and also to meet demands for respite care. The cost per in-patient week in mental handicap hospitals increased from £287.37 (at 1991/92 prices) in 1977/78 to £432.27 in 1991/92.

4.15 While more is being spent on each patient (a 50% increase in real terms) of greater interest is whether that expenditure indicates an improvement in the quality of care provided. A comparison of the running costs of the mental handicap hospitals in 1978 and 1992 shows that direct treatment costs including medical, nursing, pharmacy and physiotherapy services increased from 45% of total expenditure in 1978 to 59% in 1992. The level of nursing staff was considered inadequate in 1978 and their numbers increased progressively to 1987. As the numbers of patients have declined since 1987 so have overall staff numbers but the nursing workforce which represented 58% of the total hospital staff in 1977 increased to 70% by 1992. Qualified nurse to patient ratios have continued to improve – from 1:3.37 in 1977, to 1:2.36 in 1987 and to 1:2.03 in 1992. Over the same period the ratio of qualified nursing staff to unqualified caring staff remained constant at just over 50%.

4.16 The improved staff to patient ratios have created opportunities for the hospitals to provide a higher quality of care to a more highly dependent hospital population and to meet the demands on specialist diagnosis and treatment services associated with increased activity levels in terms of the higher numbers of short-term admissions. At the same time nursing staff perform a more proactive role in rehabilitating patients and in preparing them for life in the community.

4.17 There has been continuing capital expenditure on mental handicap hospitals – some £7.5m (at 1991/92 prices) between 1979/80 and 1991/92. The 1978 Statement set out details of a capital development programme to improve standards of care. It made particular reference to a need for improvements to Muckamore Abbey Hospital and for a reduction in the capacity of the existing villas. At that time the average number of patients in each villa was 45. A 36 bed decant unit to facilitate structural improvements to the villas was opened in 1980. The occupancy levels of all but 2 has been reduced substantially to less than 30. The remaining 2 villas have a capacity of 36 patients each but are divided into a number of dormitories and side rooms. Despite this, occupancy levels remain a matter for concern and the Eastern Board estimates a sum of £6.9m capital monies would be required to carry out essential work on the infrastructure and refurbishment of the hospital to bring the accommodation up to statutory building standards.

4.18 Although physical conditions in each of the hospitals have generally improved and the ratio of staff to patients has increased there still remain some examples of overcrowded and unsuitable accommodation. This is partly the result of changing standards of care. For example, current space per patient standards are higher than those which existed in the 1970s. Temporary localised crowding has occurred as a consequence of rationalisation of ward occupation associated with hospital contraction. There is also a lack of appropriate activities for some hospital in-patients. Measures to overcome these deficiencies have affected the rate at which retraction monies have been released. Efforts to maintain, and indeed raise, staffing ratios to cope with the higher dependency of patients remaining in hospital have also proved to be a stumbling block in agreeing the smooth retraction strategies needed to sustain the resettlement process.

4.19 The number of patients being treated in hospitals outside their Board area has fallen and is not now such a significant problem. In 1976 Muckamore Abbey Hospital provided accommodation for 58 patients from the Western Board area and 16 from the Southern Board area. By 1992 these figures had reduced to 17 and 15 respectively. In 1976 the Southern Board was providing beds for some 150 patients from other Board areas. By 1992 this had reduced to 59. The reduction in each case has largely been achieved by resettlement in the community rather than by transfer to a hospital in their Board area. Many patients remain in hospitals outside their Board area for treatment reasons, some because of a need for secure accommodation, others because contact with families and friends has now been lost. In some cases the hospital is nearer to their home than their local Board hospital.

Conclusions

- targets set in the 1987–1992 Regional Strategy for the reduction in the numbers of patients with a mental handicap in hospital were met.
- the Boards are on schedule to meet the targets set in the 1992–1997 Regional Strategy for the reduction in the numbers of patients with a mental handicap in hospital.
- the reductions in the numbers of patients with a mental handicap in hospital have enabled the Boards to achieve significant improvements in hospital care.
- the bridging finance approach to funding community care development has shown dividends.
- the flow of retraction money has not matched the reduction in in-patient numbers where there has been an absence of an agreed resettlement strategy.
- resettlement is slower than could be achieved due to a lack of care and treatment facilities and appropriate services in the community.
- admissions, mainly short-term, have increased because of a lack of care and treatment facilities and appropriate services in the community.

This section raises a number of key issues which the Report will return to later. These include:–

- the future of long-stay care beds in mental handicap hospitals;
- alternatives to short term admissions; and
- the nature of accommodation provided for discharged patients.

SECTION 5 – CARE IN THE COMMUNITY

Assessment and Care Management

5.1 The 1978 Statement stressed the advantages of comprehensive assessment on a multi-disciplinary basis. It stated that each Board should adopt guidelines for the operation of multi-disciplinary assessment which was seen as the key to providing co-ordinated advice and support for the families of mentally handicapped people and to providing comprehensive counselling services for parents at all stages of their child's development.

5.2 The 1987–1992 Regional Strategy stated that the needs of each person with a mental handicap should be fully assessed by a multi-disciplinary team. This was reinforced in Circular HSS (Mental Handicap) 1/87 'The Detection of Mental Handicap and the Assessment and Registration of Mentally Handicapped People' which contained guidance on the purpose of multi-disciplinary assessment and on the composition and functions of community multi-disciplinary assessment teams. The theme was taken up and developed in 'People First' which identified the development of a mixed economy of care and comprehensive assessment of need as the cornerstone of high quality care and stated that no vulnerable person should be discharged from hospital without a complete assessment involving all appropriate disciplines. The Department's subsequent policy guidance 'Care Management: Guidance on Assessment and the Provision of Community Care' published in 1991 asked Boards to establish a more formalised assessment process for all client groups.

5.3 All Boards have now developed implementation guidance on assessment and the necessary arrangements were put in place with effect from 1 April 1993. No person with a mental handicap is discharged from hospital or placed in a residential or nursing home without a comprehensive assessment. Parents and other carers are involved in the assessment process. Even where they decline to participate they are informed of the outcome. Boards advised the Review Team that clients in receipt of a service have a key worker and that contact points are now widely publicised for people seeking a service. However, representations to the Review team on behalf of carers suggest that much remains to be done.

5.4 Whilst comprehensive needs assessment as envisaged by 'People First' may not yet be available to all individuals with a mental handicap, mechanisms are in place to enable those in receipt of day care, residential care or who are in hospital to be assessed for their needs in that particular setting. The care provided in these various settings often complement each other. For example, residential staff are aware of elements of training or skills development to be taken forward by each client to reinforce their day care activities. Nevertheless, much needs to be done to develop packages of care offering choice for those with complex needs and meeting the needs of their carers.

5.5 The total Social Security Transfer for all client groups referred to in paragraph 4.11 will accumulate to £100.33m per annum by 1995/96. These funds are to be used to provide packages of care designed to enable people to be looked after in their own homes and where this is not possible to ensure that they are cared for in homely settings in the community. No limit has been set with regard to the placement of people with a mental handicap in any particular type of facility. The funds may, therefore, be used to maintain people in whatever type of setting best meets their assessed needs and to assist in achieving the targets set in the 1992–1997 Regional Strategy for reducing the number of patients in hospital. Comprehensive assessment of individual and whole population need is essential if these funds are to be used to best effect.

5.6 The Department is monitoring how the care management procedures are working in practice and how the care management funds are being put to use. It is carrying out an inspection of assessment procedures to ensure that they are effective. Together these measures should assist in evaluating progress on the community care reforms set out in 'People First'.

Residential and Nursing Home Services

5.7 As already indicated in paragraph 4.1, the majority of people with a mental handicap in Northern Ireland have always been cared for in their own homes and traditionally most of the remainder were admitted to hospital. In 1978 the creation of residential and day care places to help those who could not benefit from mainstream services, was seen as crucial to the development of a continuum of care which would further the normalisation process and reduce institutionalisation.

Growth in Provision

Statutory Sector

5.8 In 1978 the provision of residential care for children and adults with a mental handicap was seen primarily as a function of the Boards. The 1978 Statement did not foresee any developments in the voluntary sector (nor in the private sector) over and above the 120 places provided by the Camphill Communities. There were no nursing homes in existence or planned for people with a mental handicap.

5.9 Using a target scale, based on Great Britain norms of 0.8 places per 1,000 total population, the 1978 Statement identified a shortage of 1,038 residential places. It set as a target for 1984 the provision of 525 places in 35 new residential homes on top of the 183 statutory places in existence in 1978 and the 53 planned to open by 1982. No specific target date was set to meet the remaining shortfall. Development was to depend on the availability of resources in the face of competing needs. According to the 1978 Statement, provision at the same rate as in the first phase would have ensured completion of the programme by 1990.

5.10 By 1982 the number of places in the statutory sector had actually increased to 284 which exceeded the 1978 target by 48 places. By 1992 this figure had increased to 459. This compares with an expected total of 634 statutory places had the direction of the policy not shifted in 1987 to voluntary and private sector provision with the introduction of bridging finance and the availability of social security monies.

Voluntary and Private Sectors

5.11 The shift in Government policy over the review period paved the way for the independent sector to enter the field. Between 1982 and 1992 the voluntary sector created an additional 246 residential and 14 nursing home places providing a total of 344 places. This compares with an expected 256 places had the 1987 shift in policy not occurred. During the same period the private sector created some 160 residential and 291 nursing home places. The HHCRU Study has shown that 62% of the long-stay patients discharged from mental handicap hospitals between 1987 and 1992 were relocated in private sector accommodation. Of the 214 patients discharged between 1990 and 1992 some 61% were relocated in private nursing homes and 12% entered private residential homes.

Present Position

5.12 The overall growth in the number of places in residential and nursing homes specifically for people with a mental handicap is shown in Table 3. Although the Department would not now hold to target figures expressed in the manner set out in the 1978 Statement, the overall target identified therein of 0.8 places per 1,000 total population, ie 1,274 places, has been met. By 1992 there were 1,319 residential and nursing home places for people with a mental handicap in Northern Ireland, a more than four fold increase on the 303 residential places in 1978.

5.13 'People First' called for the development of a mixed economy of care. The percentage of places provided by each sector in each of the Boards at 31 March 1992 is shown in Table 4. On that date, 40% of community accommodation was provided by the statutory sector. The figures for the private and voluntary sector were 34% and 26% respectively. Nursing home places represented 65% of private sector accommodation and 22% of total accommodation.

5.14 By 31 March 1993 the position had altered significantly. While the number of independent sector places increased throughout 1992/93 by 250, the number of places in statutory homes declined by 50. Table 5 shows the breakdown at 31 March 1993. Of the 1,544 places available at that date 30% were provided by the statutory sector, 20% by the voluntary sector and 42% by the private sector. Nursing homes provided 27% of the total number of places available.

5.15 Whilst a mixed economy of care is apparent at regional level the range of provision at Board and particularly at Unit of Management level is not so diverse. Two Units have no statutory accommodation and 3 have a high reliance on nursing home accommodation (at least 40% of community care places are in nursing homes) thereby potentially restricting individual choice and the providers ability to meet individual need.

5.16 The level of residential and nursing home provision also varies greatly from 12.2 places per 100 people with a mental handicap in the Western Board to 19.6 per 100 in the Eastern Board. At Unit of Management level provision ranges from 22.7 in the Armagh and Dungannon Unit to 8.8 in the Craigavon and Banbridge Unit – both in the Southern Board area.

5.17 The development of community residential and nursing home facilities is designed to keep people out of hospital who do not need to be there for medical reasons. Such development should therefore result in a decrease in the numbers of patients joining the long-stay hospital population – defined as patients not discharged within 12 months of admission. In the absence of data on the number of such patients the Review Team used the total long-stay hospital population as a proxy measurement. In 1979 there were 1,425 long-stay patients in mental handicap hospitals. This figure had reduced to 1,175 in 1987 and to 814 in 1992.

Capital Funding

Statutory Sector

5.18 A full breakdown of capital expenditure on statutory residential facilities by Board is shown in Table 6. In 1978 the Department planned to make funds available to carry through a £3.2m capital development programme considered necessary to meet the target of 525 additional residential places by 1984 – a potential investment of £9.5m at 1991/92 prices. This money was to be additional to funds already earmarked in the

Department's on-going capital programme for developing facilities for people with a mental handicap. In the event, total capital spending on statutory residential facilities for people with a mental handicap amounted to £1.7m (or £3.1m at 1991/92 prices) between 1978 and 1984. It was not possible within the set timescale to secure the number of sites necessary to meet the 1984 target.

5.19 Between 1985 and 1992 expenditure totalled £2.8m (or £3.8m at 1991/92 prices). This money not only provided new statutory homes but facilitated improvements to the infrastructure of existing homes.

Voluntary Sector

5.20 Voluntary sector developments have been assisted by the Boards with capital funding. More important, perhaps, has been the funding made available by the Department of the Environment for the provision of special needs housing. Since 1979 housing associations have received capital funding totalling £5.4m (£6.1m at 1991/92 prices) to develop residential accommodation for people with a mental handicap. Of the 430 voluntary sector places available at 31 March 1993 some 328 were funded through the Housing Associations' development programme.

Private Sector

5.21 The recent development of private residential and nursing homes was accelerated by financial assistance from the Local Enterprise Development Unit (LEDU). Thirteen homes providing 240 places received a total of £0.73m (or £0.81m at 1991/92 prices) from LEDU since 1988. LEDU stopped funding in 1991 having concluded that withdrawal of the grants would not have an adverse effect on these developments.

Revenue Funding

Statutory Places

5.22 People with a mental handicap are entitled to social security benefits on the same criteria as other people in need of support though rates of benefit may be higher in certain circumstances. Those in statutory homes qualify for a lower rate of Income Support than those in voluntary or private sector homes. Since 7 May 1984 charges have been levied on people with a mental handicap in statutory homes in accordance with the provisions of Article 99 of the Health and Personal Social Services (Northern Ireland) Order 1972. Levels of Income Support invariably fall short of the charge imposed. Furthermore, special provisions apply to working residents to ensure that the charging arrangements do not remove the incentive to work. The majority of residents do not pay the standard charge. The cost of statutory residential care, which varies from £151 per week to £497 per week depending on the dependency levels of residents and the staff to client ratio, has always, therefore, largely been met by the Boards.

Voluntary and Private Places

5.23 As mentioned earlier in the Report, the main revenue support for residents of voluntary and private sector homes has come from the social security funds. It is certainly no coincidence that the rapid development of such homes started with the introduction, in 1985, of national limits of Supplementary Benefit – now Income Support. These were more generous (by as much as £40 per week per resident) than the local limits based on average charges hitherto applied in each social security office area. Furthermore, residents of non-statutory homes qualify for a higher rate of benefit. In 1986 there were only 24 private sector places – this had increased to 460 by March 1992. The number of voluntary sector places increased by 228 during the same period.

5.24 Voluntary sector homes have benefited from revenue deficit funding by Boards. Those developed in partnership with Housing Associations, also receive a Special Needs Management Allowance from the Department of the Environment designed to cover the special housing management costs of schemes. It has been an important factor in maintaining the quality of service provided by the voluntary sector. The use of Special Needs Management Allowance in the longer term is under review by the Department of the Environment.

5.25 The Residential Allowance which, since 1 April 1993, is paid as part of Income Support to people using the independent sector, but not the statutory sector, has created an incentive for Units of Management to contract with the independent sector. Potentially this could lead to a further contraction in statutory residential places which has already been apparent up to 31 March 1993.

Quality

5.26 The quality of life of residents is of prime importance. Though unsatisfactory, levels of expenditure on each resident and staffing ratios are the only measurable indicators of the quality of care over the review period. The average cost per resident week in statutory homes and hostels at actual and at 1991/92 prices in each year since 1978 is shown in Table 7. Costs have almost doubled since 1977/78. This is due largely to an overall increase in residential care staff.

5.27 Staffing figures for 1978 are incomplete but in 1985 the ratio of staff to residents of statutory homes was 1:2.1. In 1992 the ratio was 1:1.53. The staff to resident ratio in voluntary homes is 1:1.13. Comparable staff to resident ratios in private residential and nursing homes are not available. The Registration and Inspection Units require a minimum 40% to 60% ratio of qualified nursing staff to care staff in nursing homes. The majority of the qualified staff in post in 1993 had a Registered Nurse for the Mentally Handicapped qualification. The remainder had a Registered Mental Nurse qualification or were 2nd level nurses.

5.28 Most former long-stay patients with a mental handicap resettled as part of the care in the community policy were placed, in some instances by their carers, in private nursing homes while the majority of the remainder were located in residential homes. There is little evidence to show that the former were any more dependent than the latter or that homes with a higher staff to patient ratio necessarily provided the right environment for people to acquire skills or to develop their full potential. Indeed, evidence produced by the HHCRU Study indicates that the ability of many discharged patients remained unchanged or even deteriorated slightly in such circumstances. This may have implications both for future plans for resettlement of hospital patients and for the longer term monitoring of current placements in nursing homes.

Day Care Services

5.29 As with residential care, in 1978 the provision of day care for adults with a mental handicap was seen primarily as a function of the Boards and central to community care programmes.

Growth in Provision

5.30 The 1978 Statement set as a target for 1984 the provision of 700 places in 10 new adult training centres in addition to those available or in planning and due to open by 1982. At

31 December 1977 there were 1,414 places in 25 centres. By 1982 there were over 2,000 places. To achieve the 1984 target the Department planned to provide funds of £1.9m (or £5.7m at 1991/92 prices) to carry through a capital development programme in addition to its on-going capital programme for mental handicap services. Thereafter, it was envisaged that further development would depend on the availability of resources in the face of other competing needs. The initial pace of development was slower than planned with only 89 additional places being created in the period 1982 to 1984.

5.31 No target was set in the 1987–1992 Regional Strategy though it recorded that the Boards had formulated proposals for a substantial expansion in the number of adult training centre places. In fact between 1985 and 1992 a further 700 places were created. In addition to these statutory sector developments, a total of approximately 170 places are now provided by the voluntary sector. No precise information is available about private sector provision but it is thought to be limited to some in-house day care for residents of homes who do not have a statutory day care place.

5.32 The growth in the number of statutory day care places provided by each Board since 1977 is shown in Table 8. The overall target number of places set in the 1978 Statement has been exceeded. By 31 March 1992 some 1,400 places had been created providing a total of 2,834 statutory day care places including 295 places in intensive support units. The Review Team was advised by the Units of Management that, through sharing places, day care was provided for around 3,100 people with a mental handicap.

5.33 The SSI Report on Day Services recognised the importance of day care facilities in assisting the development of individual potential within the community. However, it identified the diversity of age and the needs of clients and their carers as significant factors to be considered in service provision. Such diversity also calls for an examination of the role and therefore the training needs of staff. At the same time, the SSI Report identified pressure on existing day care places and identified unmet need, not least for those requiring intensive support, as important factors in the planning process. The HHCRU Study recorded similar pressures. These emphasise a need for greater co-operation with Further Education Colleges (FECs) and other training providers in the provision of day care activities.

Capital Funding

5.34 The breakdown by Board of capital spending on statutory day care facilities in each year from 1978 to 1992 is shown in Table 9. Total spending between 1977/78 and 1991/92 amounted to £14m at 1991/92 prices. In 1987, when responsibility for the education of children with a mental handicap was transferred to the Department of Education (DENI), £5m (or £6.6m at 1991/92 prices) was made available to Boards to provide day care places for young adults who had hitherto attended special schools.

Revenue Funding

5.35 A breakdown of revenue expenditure on day care services in each year since 1977/78 at actual and at 1991/92 prices is shown in Table 10. As the table shows there has been a considerable increase in revenue expenditure – a 4 fold increase in real terms over the review period. This was matched by an increase in the number of attendances at statutory day care facilities, from 143,000 in 1977 to 545,000 in 1992.

Day Hospitals

5.36 In the 1978 Statement the Department recorded its support for the day hospital concept while acknowledging the difficulties involved. At that time day hospitals were seen as an effective means of supporting highly dependent people in the community as an alternative to in-patient care. In the event, this concept was not developed. Indeed, a facility in the Western Board, which provided day hospital care for children and adults, closed following the transfer of responsibility for the education of children with a mental handicap to the DENI in 1987. Instead of day hospitals priority has been given over the review period to development of alternative day-care facilities. A number of adult training centres have intensive support units. Although the intensity of support provided in such units is variable, in some it is regarded as comparable to the treatment and care which could be expected in a day hospital.

Care Models

5.37 The SSI Report on Day Services identified a wide variety of social, training and leisure services which are provided by the various centres and identified four recognisable models of day service practice in delivering these services. The messages and recommendations in the Report are under active consideration by Board and Unit of Management staff. The need for day centres to act as resource centres providing a link to the community by offering a range of activities on an outreach basis is increasingly recognised. It is also apparent, however, that these considerations are raising doubts about the nature and future direction of specialist day care services which should be provided. Normalisation requires that people with a mental handicap should be able to make appropriate use of the services and facilities available to the population as a whole.

5.38 The development of courses for people with a mental handicap at FECs has been a welcome development. At March 1992 there were approximately 450 people with a mental handicap attending FECs on a full-time or part-time basis as part of an Individual Programme Plan (IPP) developed at their day centre. The value of the courses to the personal development of the participants is extremely important. However, as most students return to the day centre on completion of the courses, the value of the courses is in many cases lost and they provide only temporary relief on the pressure for day centre places.

5.39 Day centre staff have also invested considerable effort in the development of work skills training designed to lead to work experience placements, vocational training and perhaps to some form of supported or open employment. They have also, on their own or in conjunction with voluntary organisations developed various work schemes and projects.

Travel Arrangements

5.40 The SSI Report on Day Services also commented on travel arrangements for people with a mental handicap attending day centres. Most are provided with free Board transport. Whilst Northern Ireland is geographically well covered by day centres, for many travelling times are too long between home and centre particularly in rural areas.

Respite Care

5.41 Respite care can be defined as any arranged break from caring provided by persons other than family members, inside or outside the recipient's home. It takes many forms and can be short or long term, be provided on an irregular or regular basis, and provide respite for either the person with a mental handicap or that person's carer. This can be particularly important where the carer is coping with a family member with severe multiple handicaps or challenging behaviour or where the carer is elderly. Indeed, 'The Burden of Care' recorded that the principal need identified by aging carers was for respite care. The survival, often into adulthood, of children with severe multiple handicaps puts an almost intolerable strain on their carers and has heightened the demand for respite services. For people with a mental handicap respite can be an equally welcome break and can be an important contributory factor in their personal development. Although, as stated, any service which relieves the caring burden may be regarded as providing respite, the following paragraphs concentrate on those which provide relief as a primary or sole aim.

5.42 Before 1978 service planners gave little priority to the needs of carers. In-patient care on a short term basis was for many carers the only practical form of respite care available. There were few alternatives for those for whom the use of hospitals for respite was unacceptable. The 1987–1992 Regional Strategy identified the provision of respite care as a main component of community support for caring families. As the move towards care in the community gathered pace the need for respite care increased. At the same time there was an increasing realisation that the use of hospital beds for respite was not appropriate and was an expensive misuse of resources. These considerations prompted the development of alternative forms of respite care.

5.43 The availability of respite services throughout the review period is not known. In recognition of the importance of respite care to the Department's care in the community policy the Review Team commissioned Mencap to carry out a study of current provision to quantify the availability of and the demand for respite care for people with a mental handicap. The Respite Care Review confirmed the importance of respite to carers and has shown that the range of services has widened considerably since 1978.

5.44 Since the publication of the 1987–1992 Regional Strategy almost all Units of Management have developed schemes by which respite is provided by host or substitute families for overnight or longer periods. Some Units of Management also arrange home care schemes which provide short breaks for the families of people with a mental handicap. Other forms of respite include summer schemes, holidays, befriending schemes and clubs. The voluntary sector has been particularly active in promoting these schemes. Nevertheless, despite these developments the range, spread and usage of current respite services remains very patchy.

5.45 Although residential forms of respite care are the preferred option of carers and the most commonly used, the Respite Care Review found that usage varied significantly from 'not at all' by 63% of carer respondents through 'once a year' by 11% to 'over twelve times a year' by 3%. However, reliance upon hospitals for the provision of overnight and 24 hour respite care has diminished as respite beds have been made available in statutory and independent sector residential homes. At 31 March 1993 there were 170 respite care beds, including hospital beds, of which 75% were in residential homes.

5.46 Community staff who participated in the Respite Care Study acknowledged local difficulties in meeting respite needs of children, people with extensive mobility problems, people with chronic health related problems and of people with a challenging behaviour. From the carers' perspective the Study found that almost half of the offers of respite care were sometimes or always unsuitable for a variety of reasons. More importantly, and contrary to staff opinion, the Study found that the majority of carers were not aware of any of the main types of respite care provision.

Manpower

5.47 The 1978 Statement called for an expansion of staff recruitment and training for residential homes and day centres. The whole time equivalent (WTE) of the total staff working in hospitals, statutory residential, and day care facilities on selected key dates is shown below.

Staff employed (WTE)

	31/12/77	31/12/87	31/3/92
Hospital	1,412.02	1,470.66	1,240.87
Residential	100.34	201.71	351.25
Day Care	186.87	492.05	674.22
Total	1,699.23	2,164.42	2,266.34

Source: RIB

5.48 In addition to staff working in these facilities there are, of course, other community mental handicap staff. Information on the numbers of such staff is not routinely collected but the Review Team asked Units of Management to quantify the WTE input of dedicated community based professionals as at 31 March 1992 to the mental handicap programme of care. They identified a WTE of 219.5 community mental handicap staff. This total was made up of 49 community mental handicap nurses, 87.5 social workers, 25 physiotherapists, 31 speech and language therapists, 22.5 occupational therapists and 4.5 other staff.

5.49 Although the number of dedicated staff working in the community has increased it is clear that the level of service provided to some groups and in some settings remains inadequate. This is particularly the case with regards to the professions allied to medicine where the available evidence indicates that in at least some Units of Management almost all of the available therapy support is provided to children in the special schools. The level of service available to adults and to pre-school children is, therefore, extremely limited. The Department's annual review of the requirements for qualified staff in the professions allied to medicine is now designed to ensure that the needs of people with a mental handicap are identified.

5.50 The need for additional clinical psychologists, foreseen by the 1978 Statement, prompted a review of the organisation of psychological services and a programme of training need was agreed. There is currently an intake of 6 students per year to the course on clinical psychology which is centrally funded by the Department. Despite this significant numbers of vacancies remain unfilled. The level of intake is kept under review and the Department is considering mechanisms to fund any increase in the number of students, should this be required.

5.51 There is a danger that professional staff working in the community can become isolated from fellow professionals. Line management structures, which are especially important where professional issues are involved, can become fragmented. The relatively small numbers of community mental handicap nurses and of professionals allied to medicine working in the community within each Unit make it difficult to ensure that there is a proper skill-mix and adequate clinical supervision, and that staff are asked to carry out tasks appropriate to their grade.

5.52 Manpower planning has taken some time to develop but a methodology has now been devised by the Department and will be refined as the necessary skills and expertise are developed within Boards. This should ensure that the manpower requirements for professional staff are identified and are fed into the planning process.

Community Mental Handicap Teams

5.53 The 1978 Statement and the Regional Strategies stressed the value of co-ordinated advice and support for people with a mental handicap and their families. Although all Units of

Management claim to have community mental handicap teams made up of social services staff, professions allied to medicine and community mental handicap nurses, the evidence available to the Review Team shows that this concept is still developing and works better in some Units than others. There are few examples of truly multi-disciplinary teams comprising different professionals working as a team under the direction of a team leader. Examples can be cited more often of distinct social work teams and nursing teams acting in partnership or some other form of co-operation and bringing in other disciplines as necessary and as available.

5.54 The role of the community mental handicap team also varies from Unit to Unit. Some have responsibility for clients from birth through childhood into adulthood. Others attend to adults only. The lack of co-ordination of professionals within community mental handicap teams, of leadership of the teams, and of a clearly defined relationship with the primary health care teams were cited to the Review Team by the Units of Management as impediments to the delivery of a co-ordinated quality service.

5.55 Community mental handicap teams are not equipped to provide the specialist treatment and care services needed from time to time by people with a mental handicap and living in the community. The necessary specialist skills are found amongst hospital staff and consequently this treatment and care has traditionally been provided in hospital. This, and the lack of suitable community facilities, has contributed to the increase, recorded in Section 4 of the Report, in short-term admission to hospital associated with the growth in the numbers living in the community.

Professions Allied to Medicine

5.56 Physiotherapists, speech and language therapists, occupational therapists, dieticians and chiropodists have an essential role in caring for people with a mental handicap and in assisting their carers. This is particularly so in the community. The development of adult training centres and social education centres created demands for an expansion of the various therapeutic services. Figures are not available for the numbers of therapists working with people with a mental handicap. However, the Department keeps recruitment needs under review and as training is to degree level, uses this information to inform discussions with the University of Ulster on student intakes.

Education, Training and Development

5.57 The 1971 White Paper 'Better Services for the Mentally Handicapped' recommended collaboration between professional disciplines as the means of ensuring, in a multi-disciplinary assessment context, that relevant professional skills would be used effectively in providing a complete and co-ordinated service. This theme was restated in the 1978 Statement which acknowledged that traditionally staff working in residential settings with people with a mental handicap had been recruited from the nursing profession.

Social Work Training

5.58 The 1978 Statement identified the Certificate of Qualification in Social Work (CQSW) and the developing Certificate in Social Services (CSS) courses as opportunities for those without a nursing background to train for residential work with people with a mental handicap. It further suggested that qualified nursing personnel undertaking such work and who wished to benefit from what these courses had to offer should be encouraged by Boards to take advantage of them. All Boards have co-operated fully in the pursuit of these recommendations.

5.59 The Social Services Inspectorate published a training strategy for the 1990s in March 1990. Amongst other things the strategy contained targets for 1996 of 50% qualified staff in statutory residential homes for people with a mental handicap and 50% qualified senior day care staff in statutory day care facilities. Both targets have already been met. The strategy also contained plans for the introduction of a new Diploma in Social Work to replace the CQSW and CSS courses. These have been put into effect. The first successful participants in the Diploma in Social Work qualified in February 1993.

Nurse Training

5.60 Training of nurses falls within the remit of the National Board for Nursing, Midwifery and Health Visiting for Northern Ireland (the National Board). In providing this training the National Board responds to demands from Boards. Community mental handicap nurses have, of course, been specifically trained to work with people with a mental handicap in the community and the mental handicap branch programme of the Diploma in Nursing (P2000) prepares nurses to work in either a hospital or community setting. A number of mental handicap nurses have undertaken post registration courses in Great Britain in behavioural therapy techniques. No such courses were available in Northern Ireland during the review period.

Joint Training

5.61 In 1982 the General Nursing Council and the Central Council for Education and Training in Social Work (CCETSW) published a report 'Co-operation in Training – Part 1'. This contained a recommendation that the two councils declare their support for the development of shared learning and issue guidelines to assist those responsible for provision to this end. In 1989 a joint committee was set up, representative of the National Board, CCETSW, the Department and Boards to promote shared learning at post qualification level. A number of initiatives have been taken forward.

5.62 Professional training generally is designed to take account of working in community care settings. Assessment of competence at National Vocational Qualification (NVQ) levels 2 and 3 is provided by the statutory sector for health and social care assistants. A number of private sector homes have also made arrangements for staff to have access to assessment of competence training. In-service training linked to staff development programmes has also been taken forward, some supported by CCETSW as part of a programme on training development.

Shift in Balance of Care

Capital Input

5.63 An analysis of total Board capital expenditure on the mental handicap programme since 1977/78 shows that alongside the capital funding which has gone towards the development of community facilities considerable capital investment has been required to maintain the fabric of the hospitals during the resettlement process. The proportion of capital investment in each of the main service areas between 1977 and 1992 is depicted graphically in Table 11. The expenditure on hospitals has impinged on the resources available for the further development of community facilities which would assist the resettlement process.

Revenue Input

5.64 Board revenue expenditure on mental handicap services in statutory facilities has increased by 58% since 1977/78 as shown in the table below. The table also shows how the shift in the balance of care envisaged by the 1978 Statement is reflected in changes in the level of revenue expenditure in each of the main service areas in 1978, 1987 and 1992. Expenditure over the review period outside these areas was not available to the Review Team.

Board revenue expenditure (1991/92 prices)

	1977/78	1986/87	1991/92
Hospitals	£20,839,664	£23,949,269	£21,660,736
Statutory Homes	£1,401,931	£4,352,066	£5,684,993
Day Care Facilities	£2,717,062	£7,273,591	£11,832,859
Total	£24,958,657	£35,574,926	£39,178,588

Source: Analysis of Running Costs

The proportion of revenue expenditure on each of the main service areas for these years is depicted graphically in Tables 12 to 15. Table 16 shows the Northern Ireland equivalent. It shows how the proportion on hospital services has changed from 83% in 1978 to 55% in 1991/92.

5.65 Total current expenditure is of course much higher than the £39.18m shown in the table above if the contribution of social security support is taken into account, particularly for those in private and voluntary sector care which was practically non-existent in 1978 and negligible in 1987. Based on the level of support available to assist residents of residential and nursing homes for people with a mental handicap – up to £195 and £260 per week respectively in 1991 – it is estimated that the contribution from this source amounted to some £9m in 1991/92.

Outcome

5.66 The developments in community facilities and services through which progress has been made in the shift in the balance of care are a consequence of the financial and other inputs outlined above. However, the success of the policy cannot be measured by input alone. The outcome in terms of client satisfaction is the ultimate test. The HHCRU Study, whilst acknowledging the difficulty of ascertaining clients' views, has shown that, despite the fears expressed by many people, former long-stay patients discharged from hospital have settled well in their new living environments. Although their level of skills may not have improved significantly they express a higher satisfaction with their new home and their quality of life.

Conclusions

- comprehensive assessment of need and matching provision to that need remains at the centre of the Department's policy for the care of people with a mental handicap.
- proper planning of services is hampered by a lack of the necessary data.
- targets for the overall provision of residential accommodation have been met (and exceeded) though not within the original timescale but levels of provision vary.
- a limited mix of accommodation type potentially restricts choice.
- day care facilities have been expanded in line with targets but day care services remain under pressure.

- an equitable balance of respite care has yet to be achieved across the Province.
- awareness of respite care services is low.
- the concept of community mental handicap teams is not working well in practice.
- joint training for nurses and social workers has had limited success.
- the shift in service provision is being delayed by an inadequate flow of resources.

This section raises a number of critical issues which the Report will return to later. These include:–

- recognition of carers needs in the assessment process;
- the long term outcome for patients discharged from hospital into residential and nursing homes;
- pressures on day care services and the role of social services staff in training for employment;
- the minimum qualifications and professional skill mixes required in nursing homes, residential homes and day centres and the need to reorientate hospital staff for work in the community;
- adequacy of domiciliary support; and
- continuing high hospital expenditure as a proportion of overall Board revenue expenditure despite a substantial reduction in in-patients.

SECTION 6 – RELATED POLICIES

Introduction

6.1 Earlier sections of the Report have dealt in some detail with specific policy and service areas for people with a mental handicap usually delivered as a specific care programme. This section covers a number of other more general areas which nevertheless impact on the lives of people with a mental handicap to some degree or other.

Health Promotion and Education

6.2 In Section 3 the Report records developments designed in accordance with the aim in the 1978 Statement to reduce the incidence and severity of mental handicap. However, health promotion and education has a much wider function. Over the review period health promotion has been increasingly seen as important in raising the health of the population as a whole. Education has played a lead role. However, little concerted effort has been made to design health promotion material which is comprehensible to people with a mental handicap.

Primary Care

6.3 No tasks or targets were set in the 1978 Statement or in the Regional Strategies in the field of primary care specifically for people with a mental handicap. However, though people with a mental handicap are affected by the same health problems as the general population, they may experience a greater variety and number. These may occur more frequently and are often masked. Furthermore, they may have additional medical conditions which arise from their underlying impairment.

6.4 General medical practitioners have responsibility for the medical needs of those living in the community. They have a pivotal role to play not only in their patients' treatment but also in their general social care. General practitioners are usually the first point of contact when parents suspect that their baby is not developing normally and often when domiciliary or other help is required. They liaise, or should liaise, with the community mental handicap teams. However, many have not had an opportunity to develop the degree of expertise needed to deal with the often complex needs of these patients. It is important, therefore, that they have ready access to specialist advice and assistance and are able to call on that advice and assistance when needed.

Dental Care

6.5 The 1978 Statement identified people with a mental handicap as one of the priority groups with a first claim on the dental services.

6.6 The operation of the community dental service throughout Northern Ireland was reviewed in 1985/6. The Review Group's Report, issued in June 1987, made particular reference to the requirements of special needs groups including those of people with a mental handicap. It recommended that children attending special schools and adults living in institutions should be inspected at regular intervals and treated as necessary; but that wherever an adult's handicap does not call for special facilities or time consuming treatment, the patient should be referred to a general dental practitioner. The Department endorsed the Working Group's recommendations and these have been implemented by Boards. Treatment requiring particular specialism is available to all people with a mental handicap in clinics located in mental handicap or psychiatric hospitals.

6.7 The Department has recently established a Working Group to advise on a Regional Oral Health Strategy for Northern Ireland. The requirements of special needs groups, including those of people with a mental handicap, for improved dental health will be considered within the Strategy.

Foster Care

6.8 Foster care is a key element of the Department's child care policy to reduce the number of children in children's homes. The 1978 Statement recognised that foster care was an equally valid alternative for children with a mental handicap. It is now accepted as an appropriate form of care although it has been difficult to obtain foster care for children with challenging behaviour or who are fragile. At 31 March 1993 there were 695 children in foster care in Northern Ireland. Although figures on the number with a mental handicap are not collected by the Department, the number is thought to be very small.

Voluntary Sector

6.9 The 1978 Statement recognised the contribution that volunteers and voluntary organisations make in supplementing and complementing statutory services for people with a mental handicap. This reflected a wider Departmental initiative which encouraged Boards to provide volunteers with adequate preparation and continuing support, to co-operate with parents and voluntary groups in the running of certain activities and facilities and to encourage and incorporate voluntary effort. The principle of continued support for volunteers and voluntary organisations still holds good and this was demonstrated in the Strategy for the Support of the Voluntary Sector and for Community Development in Northern Ireland which was published in February 1993 on behalf of all Government Departments. The Department has now established a Voluntary Activity Unit, which will take the lead for all Departments, with the aim of providing a sharper focus within Government on voluntary activity and facilitating closer liaison between Departments. The Department is also currently reviewing and updating guidance to Boards on support for voluntary organisations.

6.10 The Department provides core funding for regional voluntary organisations and project funding for schemes which have regional potential. Board funding is more widespread among voluntary groups operating at local level. In 1983/84 support from the Boards to voluntary organisations amounted to £3.4m. This would represent £5.5m at 1991/92 prices. In 1991/92 the support totalled some £9.9m – an increase approaching 100% in real terms. The total support by the Department and Boards to mental handicap voluntary organisations in 1983/84 was £224,000 (at 1991/92 prices). In 1991/92 the corresponding figure was £949,000 – an increase of 400% in real terms – demonstrating that voluntary organisations in the mental handicap field have benefitted significantly from the overall increase in funding.

6.11 Voluntary sector organisations, with Departmental and Board encouragement and financial support, have made a significant contribution to the provision and management of residential facilities, day care schemes and respite services – as indicated earlier a development, not envisaged in the 1978 Statement. Units of Management now work very closely with the voluntary sector in instigating and indeed in the running of schemes and facilities. Contracting for voluntary sector service provision, such as residential care and day care, has been introduced.

6.12 In accordance with the recommendations in the report of the Efficiency Scrutiny of Government Funding of the Voluntary Sector, published in 1990, the Department has put in place ongoing mechanisms to evaluate every three years the work of each voluntary organisation funded by the Department. Evaluators are asked to review the work of the organisation, to comment on the appropriateness of that work and to make recommendations as to future directions. Mencap and the Down's Syndrome Association, the two main regional voluntary organisations for people with a mental handicap, have been evaluated and their work has been commended. It is a requirement of project funding that each project incorporates an evaluation mechanism.

6.13 Voluntary organisations also play an active role in housing, education and leisure, and employment activities for people with a mental handicap. These functions are the responsibilities of other Government Departments and are discussed in the next section of the Report.

Targeting Health and Social Need

6.14 A new policy theme of targeting health and social need was introduced in the 1992–97 Regional Strategy. The Department and Boards are committed to identifying and, where they are found, attempting to remedy the variations in health and social wellbeing which exist throughout Northern Ireland by targeting resources where needs are greatest. The Review Team considered the extent to which variations in the needs of people with a mental handicap have been identified and whether services are being targeted to meet identified need.

6.15 As has already been indicated in the Report, there is no definitive record of the numbers of people with a mental handicap or of their degree of need for health and social care. Two studies carried out in the late 1970s and early 1980s, using data relating to people known to the then Special Care Management Committees, showed a marked geographical gradient in the prevalence of severe 'mental handicap' (measured by IQ less than 50), the lowest prevalence being in the east and the highest in the west. The numbers of people with a mental handicap in contact with Boards suggest a similar gradient, but no detailed examination could be carried out because of data deficiencies. There is no agreed interpretation of the definition of 'mental handicap'. Also, the numbers in contact with social services are not necessarily the numbers in need. In any event, the Review Team found that there were at least 1450 people with a mental handicap known to Units of Management but with whom social services had not been in contact for at least a year. Whether or not some of these people needed services then they nevertheless represent a potential need.

6.16 A Departmental review of the 1987–92 Regional Strategy identified a lack of uniformity in provision of community-based services for all client groups. More specifically the SSI Report on Day Services found that 'in each Board there appears to be an inverse relationship between supply and demand; the Units of Management with the highest identified client population have the lowest level of provision'.

Conclusions

- health promotion campaigns do not address the needs of people with a mental handicap.
- primary health care is not meeting the totality of needs of people with a mental handicap.
- dental care is available either in general dental practice, from the community health service, or in special clinics.
- foster care is difficult to arrange.
- the voluntary sector has developed significantly since 1978.

- current data sources are insufficient for identifying variations in need.

As in earlier sections this section raises three critical issues which the Report will return to later. These are:–

- the need to include people with a mental handicap in the target populations of health promotion campaigns;
- the need for specialist community services support for primary care; and
- the need to develop the expertise of primary care team members to deal with the needs of patients with a mental handicap.

SECTION 7 – RESPONSIBILITIES OF OTHER DEPARTMENTS

Introduction

7.1 The Review Team's evaluation concentrated on the Department's policy for people with a mental handicap and the services provided by Boards since 1978 to implement that policy. However, importantly, where a person with a mental handicap has the same needs for housing, education, employment, or social activities as other members of the community these should be met as part of general provision. In this section of the Report the roles of the various Departments and Agencies are examined. At the same time the Review Team acknowledges that the health and personal social services have an important complementary role to play in assisting other relevant agencies to fulfil their functions.

Housing

7.2 Housing is the responsibility of the Department of the Environment. Housing for people with special needs, including people with a mental handicap, is recognised as a priority area by the Department of the Environment, and is provided by Housing Associations. These are funded and regulated by the Department of the Environment. It provides 100% capital funding for each approved scheme. A Special Needs Management Allowance is also payable towards the cost of managing a scheme. As stated in Section 5 of the Report over 300 places have been funded. The Northern Ireland Housing Executive's draft Housing Strategy for 1995–1998 indicates that people with a mental handicap are to continue to be given a priority and that the housing association movement will meet their housing targets for the period of the Housing Strategy.

7.3 The six associations active in providing housing for people with a mental handicap offer a variety of accommodation types from semi-independent living quarters to residential homes often managed jointly with voluntary organisations experienced in providing the necessary levels of care support. These facilities have been a major contribution to implementation of the Government's community care policy. However, more could have been achieved if the various agencies had been able to co-ordinate their planning and development strategies.

Education

7.4 In 1978 responsibility for the education of children with a mental handicap lay with the Health and Social Services Boards. Consideration had been given to transferring responsibility to the Department of Education (DENI) but the Department concluded that the balance of advantage lay with the retention of schools for these children within the ambit of the Health and Social Services Boards. Of the school population of some 2,000 at that time more than half were over 16 years of age as there were no suitable alternative facilities for that group. That position remained until the mid-1980s when the policy was reviewed and changed. As a result responsibility for the education of the children, some school premises and the staff working in the schools transferred to DENI on 1 April 1987. This was a major step in the normalisation process. It not only brought children with a mental handicap into the education system for the first time but opened opportunities for such children to be educated alongside other children.

7.5 Investment in the schools when they were the responsibility of the Health and Social Services Boards was limited. Capital expenditure over the 10 years to 1986/87 was less than £3m at 1991/92 prices. In 1987 revenue expenditure on the 1,015 school age children attending the schools was estimated to be £5.1m (£6.7m at 1991/92 prices). This revenue was transferred to DENI as part of the transfer package. The decision to transfer responsibility highlighted the need to renovate or replace the existing schools to bring them up to the standard of other special schools in the education system. An additional £2m was obtained from the Department of Finance and Personnel for the initial stage of a major capital development programme. By 1992 the Education and Library Boards had made a capital investment of £8.74m (at 1991/92 prices) in the special schools, there were 1,488 children on the school rolls and revenue expenditure had increased to £9.3m reflecting an increased level of staffing, including a 44% increase in the number of teaching staff.

7.6 Responsibility for the health care and social welfare of these children remains with the health and social services. As part of the transfer arrangements, the Health and Social Services Boards were allocated £850,000 recurring revenue to increase the level of support provided by the professions allied to medicine to children in the special schools. This enabled the Boards to recruit an additional 24.5 speech therapists, 13.75 physiotherapists and 18.5 occupational therapists. Nevertheless, the overall level of therapy provision is considered insufficient by some professionals and parents. The Department and DENI are jointly reviewing arrangements for the provision of therapeutic services to children with statements of educational needs.

7.7 Health and Social Services staff still have an important role to play in the development of children with a mental handicap. They are responsible for the early, pre-school, identification and assessment of mental handicap and for notifying the relevant Education and Library Board where a child is suspected as having special educational needs. Health and Social Services staff, principally therapists, are involved in the assessment and annual review of each child's special educational needs and in the statementing process which is designed to ensure that such needs are recognised and met.

7.8 In accordance with the provisions of the Disabled Persons (Northern Ireland) Act 1989 the Health and Social Services Boards are notified by Education and Library Boards of all disabled children at age 14. The Health and Social Services Boards assess and keep under review their needs for any health and personal social services which they may require when they leave school.

7.9 The report, published in 1990, of a review of further education carried out by DENI recorded that provision in Further Education Colleges for people with a mental handicap was very limited. By March 1992 approximately 450 people with a mental handicap were attending such courses on a full or part-time basis as part of their Individual Programme Plan (IPP) developed at their day centre. Participants and staff rate highly the value of the courses to the development of individual participants.

Employment

7.10 Training for employment is the responsibility of the Training and Employment Agency. The Agency maintains a register of disabled persons through its Disablement Advisory Service. In May 1994 the register included 567 people with a mental handicap. Training places are open to all disability types but at that time there were only 25 people with a mental handicap in training.

7.11 Through its Sheltered Employment Scheme for Registered Disabled Persons the Agency places disabled people with employers and co-funds each place with the respective employer. In May 1994 there were 172 people with a mental handicap in employment through the scheme. Other measures taken by the Agency to assist disabled people find employment include the funding of aids and adaptations to the workplace and machinery and assistance with transport to work.

7.12 As explained in Section 5 of the Report, Boards have also traditionally taken a lead in training for employment as part of their day care service. The variety of training and employment schemes were examined at a conference sponsored jointly by the Department and the Agency in 1993. The conference affirmed the abilities of people with a mental handicap to compete in the job market.

Leisure

7.13 DENI and the district councils have responsibilities in the provision of social and leisure activities. As in the case of the general population people with a mental handicap need access to leisure activities as they add colour to life and provide the opportunity for stimulation, challenge and achievement. There is a growing awareness of their needs amongst providers of recreational facilities largely as a consequence of the intervention of voluntary bodies which have a long history as organisers of such activities. Anecdotal evidence exists of increasing access to recreational facilities. However, at the same time, anecdotal evidence also suggests that people with a mental handicap are often inappropriately segregated from the general population when using some leisure facilities.

Conclusions

- the housing needs of people with a mental handicap are given a priority by the Department of the Environment.
- residential accommodation development could be better co-ordinated.
- feedback from parents and voluntary groups suggests general endorsement of the transfer of responsibility for education of children with a mental handicap to DENI.
- training for employment and employment services are underdeveloped.
- access to social and leisure activities is patchy and more could be done to improve access to leisure facilities and to reduce unnecessary segregation.

The transfer of responsibility for education to DENI raises issues concerning school leavers including further education, training and employment, and day care to which the Report will return later.

SECTION 8 – EVALUATION SUMMARY

Introduction

8.1 This section looks at the inter-relationship of the objectives in the 1978 Statement, and subsequent documents, for each policy aim and the cumulative effect of the steps taken to implement them; sets out the main conclusions to be drawn; and identifies the key issues to be considered to ensure the further development of effective high quality services.

Prevention

8.2 The paramount importance of preventing mental handicap was emphasised in the 1978 Statement. The Baird Report contained a number of recommendations which collectively constituted an interventionist policy and effectively set tasks and targets for the various objectives pursuant to this aim.

8.3 Evaluation of the policy over the review period has not been a simple matter. As recorded earlier in the Report, the numbers of people with a mental handicap over the review period are not known nor are the total numbers of babies born with a mental handicap each year. It was not possible, therefore, to quantify with any certainty the cumulative effect of the various measures taken since 1978 to prevent mental handicap. Nevertheless, the Review Team was able to establish that steps have been taken to implement the recommendations in the Baird Report. It found that with one or two exceptions substantial improvements have been achieved.

8.4 Whilst there have been considerable developments in health education in Northern Ireland since 1978, focus has been given to issues which affect the general population. Specific advice on the prevention of mental handicap has not enjoyed as high a profile as other issues. Over the review period, uptake rates of the various vaccination programmes have increased significantly to the point where community immunity is achievable. Evidence shows that such programmes have resulted in dramatic reductions in the incidence of the relevant diseases. There are, however, wide variations in vaccination uptake rates at Board level. Although based in Belfast the genetic counselling and screening service is provided as a regional service. Full implementation of the recommendations in the Baird Report for the development of the service has been hindered by a lack of adequate funding. Insufficient staff levels are preventing the development and proper use of a comprehensive genetics register and the expansion of counselling clinics and screening. As a consequence the service has not reached its full potential.

8.5 Improvement in maternal and child health care has been a policy priority throughout the review period and has been accompanied by reductions in mortality rates though variations exist at Board and local levels. Continuing improvement remains a priority and maternal and child health are identified as one of the 8 key areas of concern in the 1992–1997 Regional Strategy. Boards have been asked to evaluate their programme against regional outcome measures.

8.6 Whilst the absence of data does not allow the Review Team to confirm the effectiveness of the Department's interventionist objectives, the Team remains convinced of their relevance to, and the importance of, the prevention of mental handicap. Key issues which need to be addressed are:-

- targeting health education;
- increasing vaccination uptake rates; and
- developing genetic services.

Normalisation

8.7 Normalisation has been the fundamental aim of the Department's policy for the treatment and care of people with a mental handicap. At the same time the policy did not imply that people with a mental handicap can lead fully normal lives or have no special needs. Rather normalisation recognised their need for special help and emphasised that this help should be designed to enable each person to attain the maximum development consistent with his or her degree of handicap.

8.8 The normalisation objectives in the 1978 Statement and later documents have been pursued by a twofold approach – rehabilitation of those in hospital who did not need that level of care and avoidance of inappropriate admission to hospital of those living in the community. Achievement has been sought by the assessment of need; provision of community facilities and services to meet the assessed need; and the development of tailored packages of care.

8.9 The shift to community care has been accompanied by the provision of a diversity of community facilities, particularly in the form of residential and nursing homes and day centres, and an associated expansion of community health and social services. The cumulative effect has been a reduction by 31% from 1,337 in 1978 to 926 in 1992 of the number of patients with a mental handicap in hospital. By 1993 only 9.5% of people with a mental handicap were long-stay hospital patients, 18% lived in alternative accommodation in the community, and the majority, 72%, lived at home with their families.

8.10 Against the falling long-stay hospital population, however, there has been a four fold increase in the number of short-term admissions to the specialist hospitals reflecting a lack of treatment facilities and services in the community capable of meeting specific medical, nursing and therapeutic needs at the required time. The admission rate may, of course also reflect an acknowledgement that the hospital beds are available.

8.11 Despite the achievements outlined above, the Review Team is of the opinion that more could have been achieved in the shift in the balance of care from hospital to the community if more funds had been released from the hospital services. Although the percentage of expenditure on hospital services fell from 84% of overall expenditure on mental handicap services in 1978 to 55% in 1992, the actual expenditure on hospital services increased in real terms over those years.

8.12 Ongoing expenditure on hospital care, if sustained at current levels, will continue to impede the development of community care. Concern was expressed to the Review Team that insufficient funding was being made available to meet the rising cost of resettling the highly dependent patients currently being cared for in hospital. However, the Review Team is of the view that if agreed retraction strategies are put in place, the consolidation of the bridging finance in Boards' baseline allocations coupled with subsequent retraction monies and the Social Security Transfer should be sufficient not only to meet the 1997 targets but to quicken the pace of resettlement.

8.13 All the evidence available to the Review Team suggests that since 1978 normalisation has been the right policy. The HHCRU Study, whilst acknowledging difficulties in ascertaining the views of many people with a mental handicap, concluded that from their perspective community care based on assessment of individual need and the provision of tailored packages of care is preferable to long-stay hospital care. However, it is clear that the ideals envisaged in 1978 have not all been achieved. Services designed to promote normalisation have in many respects prevented the inclusion of people with a mental handicap in the normal life of the community. Furthermore, new priorities and pressures are emerging, such as the increase in the survival rate of babies with profound mental handicaps and the increased longevity of people with a mental handicap which will tax the type, level and range of service development into the next century.

Conclusion

8.14 In addition to the key issues listed at the end of each preceding section arising out of its policy evaluation and its discussions with staff at Board and Unit of Management level, the Review Team identified the following as crucial to the future development of the policy:-

- there is an urgent need for basic planning and monitoring information which must be rectified if the care in the community policy set out in 'People First' is to be properly implemented;
- prevention of mental handicap remains a fundamental aim and health education, vaccination and genetic services are essential components;
- a fundamental shift in resourcing is required to fund the development of the range of facilities and services needed to meet the community care needs of all people with a mental handicap; and
- more needs to be done to integrate people with a mental handicap within their local communities by including them in society through improved access to the services provided by other agencies.

Proposals for strengthening the policy with particular reference to the key issues are set out in Section 9 of the Report.

SECTION 9 – THE WAY FORWARD

Introduction

9.1 The previous section of the Report summarises the findings of the evaluation of the various policy aims and components contained in the 1978 Statement and identifies key issues considered as crucial to the future development of the policy. In this section the Review Team examines these key issues, draws a number of conclusions, and makes recommendations designed to refocus policy objectives on the needs of ***people with a learning disability*** to the end of the century and beyond. As explained in Section 2 the Review Team accepts that the term 'learning disability' is more widely preferred than 'mental handicap' and accordingly has recommended that it be used by the Department in future. It is the term used in this section of the Report.

9.2 The Review Team has deliberately not set specific targets for the future development of services. Similarly, it has not attempted to set an agenda for the treatment and care of all the divergent and emergent needs of people with a learning disability. The Review Team believes this is part of the planning process. Its role is rather to paint the broad policy canvas from which planners, purchasers and providers and their staff can draw inspiration in mapping the way forward. It is for the Department, other Government Departments and their respective agencies to develop implementation strategies. In the field of health and personal social services it is for Boards to examine the recommendations and, as purchasers, to set targets in the light of assessed need, and for HSS trusts, Boards' Directly Managed Units (DMUs) and the independent sector to rise to the challenges set by the purchasers.

9.3 As already stated in the Report the Review Team recognises that hospital services and health and personal social services in the community are not separate entities but constitute elements of the continuum of care – a continuum which extends beyond health and personal social services and embraces such matters as education, employment, housing, leisure etc. Nevertheless, in mapping the way forward the Review Team has concentrated on those elements which are the responsibility of the Department. To establish a focus for its recommendations these elements are examined in turn.

Clients' Needs

9.4 Clients' needs and expectations have changed over the review period. Indeed, in many respects when the 1978 Statement was drafted these were determined not by people with a learning disability but by their carers and professionals. Today clients expect, and it is recognised that they have a right, to contribute, either directly or through advocates, to the decision making processes which affect their futures collectively and individually. They expect and have a right to expect equal status, access to mainstream services, and assistance, commensurate with their special needs, designed to enable them to benefit from those services.

9.5 Developments in medical intervention have resulted in the emergence of a group of babies born with profound learning disability who are surviving into childhood and beyond. Many in late childhood and in adolescence display challenging behaviours. At the same time increased longevity enjoyed by the general population extends to people with a learning disability with even more pronounced effect. These factors are adding to the increased diversity of age and disability of this group. As diversity has increased so has understanding and interventions which can lessen the impact of disability.

9.6 To provide the range of services and facilities necessary to meet the resultant diversity of needs of people with a learning disability, the Review Team wishes to reiterate that **multi-disciplinary assessment and regular reviews of individual needs are required.** A diversity of provision must be put in place if continued inappropriate care is to be avoided when existing care plans are found no longer to meet need. Care management is being progressively developed. DMUs believe that the mechanisms put in place will not only help deliver a better service to clients and their carers but will assist the Boards in establishing the level of overall unmet need and identify purchasing priorities. It is important that these procedures develop as intended and do not in themselves become barriers to service development.

9.7 Although outside its remit the Review Team is concerned that children and adults who are not assessed as having a learning disability, but who nevertheless might be regarded as borderline cases, are not generally seen as needing specialised services and consequently receive inadequate support. It is for Government Departments and their agencies to ensure that their needs are not overlooked.

Carers' Needs

9.8 Carers of children and adults with a learning disability have similar needs to those of other caring members of society. Their needs are often more pronounced especially when those being cared for have profound disabilities, complex needs or exhibit challenging behaviour. New parents have particular needs which require sympathetic and knowledgable responses from the moment it is suspected that a baby may be affected by a condition which could be disabling. As people with a learning disability live longer their carers age, and so caring becomes increasingly difficult. To enable carers to maintain their valuable contribution to the spectrum of care, **Boards must have regard to carers' needs, including training, when developing their purchasing plans, and HSS trusts and DMUs must identify carers' individual requirements for health and personal social services as part of client assessments.**

9.9 It was reported to the Review Team that many carers experience difficulty in accessing services and service providers, and once contact is made in maintaining that contact. Regular monitoring and review of the means by which services are publicised and the arrangements designed to ensure continuity of service are necessary if these difficulties are to be eradicated.

Information Needs

9.10 The Review Team's evaluation of the 1978 policy was seriously hampered by a lack of data. **There is an urgent need for Boards as purchasers, and HSS trusts and DMUs as providers, to identify their data requirements**, and put mechanisms in place for the collection of those data. As a minimum, data is required for needs assessment, identification of unmet need and inequity in access to, and the use of services, and for service planning and monitoring. Only then will purchasers and providers be able to implement the policy as proposed in the following paragraphs and measure achievement. It is equally important that **the Department should stipulate its information needs** for strategic planning and monitoring purposes and future policy evaluations. To avoid duplication and ensure comprehensive and comparable data are collected the Review Team recommends that **the Department, Boards and HSS trusts should agree common data requirements and definitions.**

9.11 **In the absence of an official register of people with a learning disability, HSS trusts and DMUs should devise alternative arrangements for collecting, collating and updating basic information.** A minimum data set should include numbers, by age, location, level of dependency due to learning disability and any associated physical or sensory impairment, the family support provided and the needs of carers, not only of those who are currently receiving a service, but of those who may require a service in the future. This information should be held on a single data base within each HSS trust and DMU. It would enable providers to be more aware of, and plan a range of, services to meet purchasers' requirements, and to determine the number and type of staff required to deliver those services and hence their cost. As demands on services increase resource implications will assume even greater significance. Aggregation of these data at Board level should assist Boards to target health and social need, set priorities and to be specific about the totality of the service which they wish to purchase. **Needs can only be assessed by an open and full exchange of information.** Internal market considerations must not be allowed to interfere with this exchange. The need to keep data up to date implies that service providers should continue to assess the needs of not only those receiving support but, so far as is possible, those who, for whatever reason, are not in receipt of care or treatment.

Research Needs

9.12 There was a notable lack of research in Northern Ireland throughout the review period into aspects of learning disability. This added to the difficulties experienced in carrying out the policy review. Accordingly, the Review Team recommends that **the Department should include learning disability in its priority areas for local research taking account, of course, of research conducted elsewhere.**

Core Values

9.13 Much of the philosophy behind the principles set out in the 1978 Statement and reproduced in Annex 5 still has general application. They have served the policy well in the intervening period. However, much has changed over that period and their wording is now too out-dated and circumscribed to have an impact in the run up to the 21st century. Consequently the Review Team has put forward a new set of principles designed to take into account clients and carers aspirations to citizenship, inclusion, education and employment – principles designed to ensure a brighter and more fulfilling future. These are set out in Annex 6. The Review Team has also identified 6 service principles which reflect the Government's recognition of the rights of people with a learning disability as individual citizens. These are set out in Annex 7. Together the principles constitute the core values which will support the policy in the next decade. They underpin the key policy objectives for the future and how these objectives might be pursued in specific service areas. The Review Team recommends that **all agencies contracted to work with people with a learning disability should be required to subscribe to the principles underpinning the policy.**

9.14 The quality of life of residents is of prime importance but has hitherto been to some degree a matter of chance. **The quality standards now being set by Boards should provide a better means of assessing quality of life.** The Review Team recommends that **quality standards should be clearly set out, accessible to users and monitored under contract.** The Registration and Inspection Units established in each Board area also have an important role to play by promulgating standards which will improve the quality of life of the residents of homes.

Health Promotion

Health Education

9.15 The 1992–97 Regional Strategy recognises that the Health Promotion Agency, Boards, professionals and General Practitioners all have a role in giving advice. That role now extends to HSS trusts. Schools also have a health education function. The Review Team believes that **a higher profile should be given in health education to the risks of learning disability.** At the same time the Review Team would suggest that **the Health Promotion Agency should examine the merits of a programme, focused at couples at risk of having a baby with a learning disability.**

9.16 Health education, of course, has a much wider function in the field of learning disability. People with learning disabilities have the same need as the general population for healthy lifestyles and prevention messages delivered in a manner that they can understand. People in general including health and social services staff would benefit from well focused programmes in understanding and accepting people with a learning disability.

Vaccination

9.17 The 1992–1997 Regional Strategy has set 95% uptake levels for all primary immunisations. As these levels are approached improvement becomes increasingly difficult. The Review Team endorses the advice contained in the Department's Maternal and Child Health Action Plan designed to achieve an uptake rate for all primary immunisations across Northern Ireland.

Genetics Service

9.18 Genetic counselling is identified as a critical issue in the 1992–97 Regional Strategy. Up to 3% of couples are at high, and recurrent, risk of having children with an inherited disorder. The Review Team supports the objective in the 1992–1997 Regional Strategy that each Board should ensure that it has access to genetic counselling services, so as to minimise the risk of a child being born with a genetic abnormality and hence reduce the prevalence of disability.

9.19 This does not mean that the service should cease to be provided on a regional basis. The Review Team is of the view that **the service should continue to be purchased jointly by the Boards and delivered by a single provider.** Any fragmentation of the service could seriously affect its effectiveness and result in inequality of provision and access. However, **an expansion of clinics, on a geographical basis, should provide a more localised and accessible service.** Nevertheless, the Review Team is of the view that this alone will not ensure the desired outcome of the Department's objective. To effectively reduce the incidence of genetic disorder at birth **all potential parents with a family history of genetic or chromosomal disorder should be offered genetic counselling.** Wherever possible this should be done prior to conception so that informed choices can be made from the full range of options available.

9.20 The recommendations of the Royal College of Physicians on prenatal diagnosis and genetic counselling in England published in 1989 have equal validity in Northern Ireland and are as valid today as they were in 1989. They are reproduced in Annex 8. **It is essential that professionals counselling couples at risk of conceiving a child with a genetic abnormality are fully informed of the benefits of genetic counselling and of the available services.** They must also be aware of the need to keep parents informed at all stages of the programme as inadequate counselling and advice can lead to confusion and anxiety. It is through non-directive genetic counselling, supported by accurate diagnosis and risk assessment, that individuals and couples are enabled to arrive at informed decisions regarding life planning, parenthood or the outcome of their pregnancy. Furthermore, the introduction of any new intervention programme must be accompanied by comprehensive training of professionals at all levels of the service.

9.21 As diagnostic techniques improve so does the potential value of the Northern Ireland genetics register. That potential is being missed through lack of investment. **The appointment of sufficient consultancy and support staff is a prerequisite to maximising the potential benefits of the genetics register.**

9.22 The Review Team recognises that the measures set out above may create a demand for screening which the service could not meet within existing resources. That need not necessarily be an argument for unlimited additional funding. **The Regional Medical Services Consortium should consider the future development of the service** having regard to the cost effectiveness of the various interventions now available and the medical and ethical issues which may affect demand in Northern Ireland. Any review of the service should take into account management and support systems and structures, clinical supervision, and resource considerations.

Maternal and Child Health Services

9.23 Maternal and child health is identified as a key area of concern in the 1992–1997 Regional Strategy. The Review Team endorses the objective in the Strategy that each Board should develop systems for multidisciplinary assessment and management of children with complex disability.

Inclusion

9.24 The 1978 policy aim described as ***normalisation*** is today regarded by many clients and carers alike as patronising and not appropriate for the 21st century. Their aspirations now extend beyond the normalisation principle of integration and focus on **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.

9.25 The Review Team accepts that now is the time to set aside normalisation as a policy aim and recommends that hitherto **the aim of Government policy for people with a learning disability should be inclusion.** It is for Government and society to include people with a learning disability as they would any member of society and to accept them for who they are and the way they are.

Hospital Services

Reducing the Hospital Population

9.26 The Review Team has no doubt that care in the community remains the preferred option for the long-term care of all people with a learning disability. Long stay in hospital is no longer acceptable as an option for people with a learning disability and who need continuing care. The Review Team is of the view that **resettlement of those in hospital should be pursued with the utmost vigour as a primary objective.** However, if the pace of resettlement is to increase measures need to be taken to avoid the problems faced in the past. **Purchasers and providers need to develop longer-term resettlement programmes designed to quicken the pace of discharges with agreed retraction strategies designed to release the funds required to provide the necessary additional community based services.**

9.27 Resettlement programmes cannot be developed without a free exchange, between purchasers and providers, of information about patient and carer profiles, individuals' needs, preferences and expectations. A wide range of facilities and expertise has been developed in the community and staff based in the community are perhaps more aware of the potential of these facilities for meeting the varying needs of the present hospital population. With a view to avoiding misplacement and possible consequential deterioration of skills **community based staff should have full access to hospital in-patients and their records.** This would put HSS trusts and DMUs in a better position to determine need and to plan to meet that need. It would also facilitate the design of individually tailored rehabilitation programmes.

9.28 Existing financial arrangements have been a major obstacle to resettlement. Boards already sub-contract with HSS trusts and DMUs for the provision of residential and day care. They could equally do so for hospital care. Such an arrangement would give them a greater incentive to plan packages of care which are wholly appropriate to patients' needs in the community. The Review Team recommends that **each HSS trust and DMU providing services in the community should be given the funding to pay for the specialist hospital needs of their resident populations.**

9.29 Hospital staff have reported that there are few patients who could not be discharged if suitable alternatives were developed. As these alternatives are provided the continued reduction in patient numbers will bring the viability of the learning disability hospitals as currently established into question. It follows that **specialist hospitals must contract to the minimum level commensurate with the numbers of patients needing assessment and short term treatment which cannot be provided in their permanent home or elsewhere** and the smaller numbers who may require intensive treatment over longer periods of time. In addition, as the hospital population continues to decline, **consideration should be given as to whether the current specialist hospital based services and staff should be formally reorganised on a community basis** even if they continue to retain some hospital responsibilities. **Boards need to decide now as to their future requirements for hospital provision and, in consultation with all concerned, how a smooth run-down of the existing specialist hospitals can be achieved and alternative, community services and facilities can be put in place.**

Improving Hospital Services

9.30 **Specialist hospitals of the future should be smaller, more accessible and less institutional than those of today.** Admission to a specialist hospital should only be necessary where specialist services and facilities are required for the assessment or treatment of learning disability and associated mental health or behavioural problems, or where semi-secure accommodation is required for the management of patients, including offenders, detained under the Mental Health (Northern Ireland) Order 1986. Unless there are clear medical reasons for admission **hospitals should not be used for the provision of respite care.** Long-stay care in hospital should not be an option for anyone referred for care management.

9.31 In keeping with the principles of inclusion the Review Team recommends that **the needs of people with a learning disability for general medical treatment and recuperation should be met in the ordinary way in a general hospital.** Likewise, psychiatric treatment can be provided in psychiatric wards of general hospitals. When required support should be given to general hospital staff by specialists in the treatment and care of people with a learning disability. Indeed, areas of joint collaboration and training of medical staff in general psychiatry and those specialising in learning disability should be fostered.

9.32 The Department's policy is that no child should be brought up in hospital and while in hospital children should not mix with adults. There is evidence of an increasing number of young people with challenging behaviours, mental health problems and severe physical handicaps. There is also evidence of a recent increase in admission rates of young people to hospital and of the number staying in hospital for long periods. Their needs should be met in the community by the development of appropriate treatment facilities and services such as specialist support in the child's home, or alternative arrangements for treatment in residential and day care settings. **Boards and HSS trusts must take steps to address emerging pressures to ensure that a new generation of children do not become long-term hospital patients.**

9.33 **Children with a learning disability who require general hospital services should be admitted to paediatric departments.** Difficulties arise in providing suitable general hospital accommodation for adolescents with a learning disability. Adolescents have distinctive needs which are different from both child and adult patients. Ideally they should be accommodated in separate units within childrens' wards. This is not always possible but **every effort needs to be made to ensure that hospital accommodation, facilities and staffing provided for adolescents are appropriate to their emotional, physical, social, educational and developmental needs.**

Care in the Community

Introduction

9.34 Community care is designed primarily to enable people to live in their own homes through the provision of individually tailored packages of care including, where necessary, domiciliary support consistent with identified need. These should draw on the services of the various specialisms, professional or otherwise, whether provided by the statutory, voluntary, or independent sectors. It is essential that clients and their carers are informed about the services available, and have access to and receive the level of support needed to maintain them within the community. It is also important that these services are delivered as locally as is feasible. **Purchasers and providers of support need to ensure that a co-ordinated and responsive service is available to meet identified need.**

9.35 There will continue to be a core of patients with chronic physical or sensory disabilities and/or severe behavioural problems who require hospital type care on a continuing basis. The complex needs of these individuals should not mean continuing long-stay hospital care but should be addressed by developing alternative forms of care in the community.

Residential and Nursing Home Services

9.36 In recent years there has been a marked reduction in the numbers of statutory residential places for people with a learning disability. However, from a policy perspective **there is a need for the retention of a minimum level of statutory services.** The position cannot be assessed in purely financial terms. A loss of direct management and expertise in this field of provision would leave an uncomfortable gap in any portfolio of service provision. Also, an imbalance in provision potentially denies choice. Nevertheless, it is unrealistic to expect statutory authorities to maintain empty beds to act as a rescue service in the event of the closure of independent sector homes. Services must, therefore, be planned to meet these apparently opposing requirements.

9.37 There are conflicting views about the relationship of the size of residential and nursing homes to the quality of life of residents. Many views were expressed to the Review Team but a clear consensus on the maximum or, indeed, optimum size of homes did not emerge. The Review Team is of the opinion that **intangibles such as the mix of clients, the staff mix and regime, and the pattern of the residents' day, can be more important to quality of life than the overall number of places in a home.**

Nevertheless, the Review Team believes that larger homes by their very nature cannot be as homely as smaller homes.

9.38 The Review Team does not take the view that limits should be set on the numbers of residential and nursing home places to be provided for people with a learning disability. Rather the Team believes that more imagination is needed, having regard to age and potential length of stay, in providing a diversity of accommodation with the emphasis on as independent living and domestic settings as possible such as family placements, supported housing and core and cluster homes. Care must be taken to ensure that placement in a residential or nursing home is not in effect an exchange of one institutionalised environment for another, particularly in cases where clients are relatively young and could potentially spend many years in such homes. Special attention is required where children need care outside their family home. **It is for purchasers, taking appropriate advice, to decide on the range and size of the residential and nursing home provision that they wish to purchase having regard to the inclusion policy aim and the assessed needs of individual clients.**

9.39 The Review Team would reiterate that **it is essential that proper multi-disciplinary assessment takes place prior to placement and that where placements are made that periodic reviews are undertaken to ensure that the form of care agreed prior to placement remains appropriate.** The HHCRU Study found that a high proportion (82%) of long-stay patients discharged between 1990 and 1992 were resettled in highly staffed accommodation, mainly residential or nursing homes. For many, more domestic environments, where residents are encouraged to do more for themselves, may promote greater independence through the enhancement of skills and consequently maximising their potential.

9.40 The Review Team endorses the view expressed by the HHCRU Study that **all settings should be encouraged to implement approaches to care designed to further development of skills and autonomy.** At the same time **Boards need to consider whether the placements arranged for discharged patients remain the most appropriate in developing skills and autonomy.** The onward movement of some residents would free up the places needed to accommodate the more dependent people still in hospital and have complex needs who will require care in a highly sheltered environment. Maximising levels of function would facilitate this process. It is equally important that all other elements of the package of care, including day services are similarly reviewed.

Day Services

9.41 The value of day services cannot be denied. They offer an opportunity, for many the only opportunity, to socialise, to meet and make friends, as well as scope for fulfilment and self-esteem through training, education, work and leisure. Although not their primary function day services also offer respite for carers. Few day services, however, provide opportunities for inclusion and indeed day care centres can perpetuate segregation and in some cases may encourage dependency.

9.42 For too many school leavers traditional day care centres are the only option in the continuum of care. The vast majority of children with a learning disability attend special school until they reach 19 years of age. The general expectation of teachers and service providers, and in many cases their carers, has been that they will then progress to a day care centre where the Health and Social Services Board will assume responsibility for their continuing care. However, many young people with a learning disability today have higher expectations.

9.43 It would appear that an opportunity is being missed during pupils' time at school to identify, and to steer those who have exhibited an ability to benefit from further education or work training directly to the appropriate services. Other agencies including Further Education Colleges and the Training and Employment Agency are continuing to develop the necessary expertise, to undertake this role. The need for, and the ability of, personal social services staff to duplicate these roles and responsibilities needs to be examined. Rather, health and social services staff working with school children should be alert to each child's potential and bring these to the attention of those who have the appropriate skills. **People with a learning disability who can benefit from further education of training for employment should be directed to the appropriate statutory body and should be entitled to expect the same opportunities as all other members of society.** Encouragement by the appropriate statutory body might stimulate uptake of these alternative services.

9.44 When training for employment or further education, which may lead to work experience, is being considered, carers must be consulted and reassured. Many carers have natural concerns about their family member leaving the security offered by a day care centre. Many have concerns about the possible adverse effect of the loss of social security benefits. Such concerns are genuine and must be addressed when alternatives to day care are being considered. **Trainees and carers must be made aware of the commitment being expected of them when training for employment is proposed and make that commitment before training commences.** At the same time they need to understand that those opportunities will not always lead to progression and may not result in employment. In such circumstances, trainees may have very negative feelings about returning to a traditional day setting. Consideration needs to be given as to what form of day activity would be appropriate to maintain skills.

9.45 Not all people with a learning disability will, of course, be able to benefit from a work related or further education programme. Their needs may cover a spectrum from social training to very intensive care. However, the diversion of those who can benefit into other spheres, should free care staff in day centres to concentrate their skills on those who need them most, and to provide a higher quality service. For those needing very intensive care nursing, medical and paramedical support should be available. While the development of social skills training may be best achieved in a day centre **every opportunity needs to be taken to plan day services on an outreach basis and to make use of facilities and services available to the general public.** This will entail a greater recognition by other agencies of their responsibilities. An added advantage of outreach especially in rural areas can be a reduction in travelling time.

9.46 The continued diversion of people with a learning disability from hospital will put additional pressure on existing and planned statutory day care places. **It is essential, therefore, that Boards and HSS trusts should seek ways to reduce the pressure on statutory day care places. They should encourage input from the independent sector and involve other agencies, such as the Arts Council, the Sports Council, District Councils and youth and community groups, in providing a choice of day activities appropriate to assessed needs.** Activities for those in residential accommodation are particularly important. These measures should enable statutory providers to target their day services at those with greatest need.

Multi-disciplinary Community Teams

9.47 The Review Team is of the opinion that multi-disciplinary community teams have a vital role to play in assessing need and in providing services necessary to support people with a learning disability in the community. **Each HSS trust and DMU needs to consider and determine the role of its community team, its leadership, composition and management to ensure the provision of a co-ordinated, quality service, and publicise how it can be accessed.** Service provision must be based on the needs of users rather than the priorities of professional groups. **For people with a learning disability it is particularly important that their needs for therapeutic services be taken fully into account:** speech and language therapists, physiotherapists, occupational therapists, chiropodists and dieticians all have a role to play. It is important, therefore, that their skills are recognised and appropriately utilised. It is also important that appropriate arrangements are put in place to provide professional supervision and support to team members and to develop their skills.

9.48 **Service providers also need to examine the relationship and lines of communication which are needed between multi-disciplinary community learning disability teams, specialist services, GPs and primary health care teams.** This should ensure that proper assessment of need is achieved, that care and support is co-ordinated and that mechanisms exist for the review of individual care programmes.

Specialist Support Services

9.49 At times of crisis admission to hospital has often been the only response. However, admission to hospital even for short periods disrupts continuity of care in the community. To avoid this and unnecessary short-term admissions to hospital the Review Team recommends that **specialist peripatetic community intervention teams should be deployed to work in partnership with primary health care teams.** These should be capable of delivering a 24 hour high level emergency service and, if necessary, arranging longer term support over a protracted period. Such intensive support could be provided by the teams in designated facilities or from them on an outreach basis. However the teams operate, the specialist support must be made available if ongoing community treatment and care programmes are to be maintained. A deterioration in the condition of many living in the community through lack of such support could lead to their becoming institutionalised and prevent achievement of hospital retraction programmes.

9.50 The Review Team recognises that the expertise needed is mostly confined to a limited number of staff currently employed in hospitals. At the outset, therefore, the types of service envisaged may have to be provided by HSS trusts and DMUs on a shared basis. However, this should not be allowed to become a permanent arrangement. Efforts should be made to disseminate the necessary knowledge and develop the necessary skills to facilitate more localised provision.

Staff Education, Training and Development

9.51 **Everyone, whether professional or otherwise, involved in the treatment and care of people with a learning disability should have an appropriate qualification.** Each discipline should, therefore, determine the minimum qualifications necessary to ensure staff have the skills and competencies to provide quality care for this client group. Each discipline should conduct a training needs analysis and arrange relevant training to meet identified need. Existing staff should be encouraged and given the opportunity to acquire these qualifications and to undertake further training including in-service and joint training.

9.52 With the development of multi-disciplinary team working and mixing of skills **opportunities for cross professional training should be explored and exploited.** Co-operation between the statutory, voluntary and private sector providers is equally important with the development of the mixed economy of care and the dispersal of expertise associated with the diversity of care provision and providers. **Hospital staff who have not had experience of working in the community should be given appropriate preparation for that role.**

9.53 There is a need to enhance undergraduate and postgraduate medical education and training in learning disability. GPs have a particular need for ongoing training. The

Review Team recommends that **relevant courses should be included under the post graduate training allowance scheme for GPs.** Where appropriate use should be made of multi-disciplinary opportunities.

Respite Care

9.54 Home care inevitably puts more pressure on family carers than on anyone else. More people than ever, including many more people with profound disabilities and complex needs or behavioural problems, are being cared for at home with, and without, professional and voluntary support. As people with a learning disability live longer so their carers age. For all carers respite from their often traumatic and tiring role is a prime need. Respite can be for a few hours or for a number of weeks.

9.55 The Review Team endorses the conclusions of the Respite Care Review that **well publicised, imaginative and responsive respite schemes, which are flexible, local, accessible and which are tailored to meet the needs of carers, are required if carers are to be able to sustain their caring role. The continued use of hospital beds for respite purposes is not appropriate.** Similarly, Boards should seek to develop alternatives to attendance at day care centres as primarily a form of respite care.

Related Policies

9.56 Whilst the policy concentrates on health and social services delivered specifically for people with a learning disability it recognises the impact of related policies on their well being. The development of the internal market between purchasers and providers, contracting with voluntary and private organisations, GP fundholding and of targeting health and social need could each have an ongoing impact on the provision of services and how they are allocated and developed. Importantly, the Department is currently considering the range of personal social services for which individuals may be charged. This will have implications for people with a learning disability.

9.57 Early detection and treatment of learning disabilities can in many cases lessen the severity of resultant disability. It is important, therefore, that all involved in the child health surveillance programme, and in the school health service, be aware of the need to refer at once any child who they suspect may have a disability.

9.58 For many people with a learning disability living within the community the GP is often the first point of contact when general or specialist medical help is required, either routinely or in an emergency. Early detection of health problems and appropriate intervention can have beneficial results. **It is essential that GPs and other members of the primary care team are constantly alert to the possible need for specialist services for their patients with a learning disability and their carers.** General practioners have a responsibility for the health of their patients. The Review Team recommends that **GPs and other members of the primary care team should adopt a pro-active approach to ensure that the general health, and indeed other needs, of those with a learning disability are detected** as not all will come forward when health problems arise.

9.59 Where treatment calls for specialist medical, nursing, therapeutic or social services, primary care team members need to have effective access to those services whether they are to be provided in the patient's own home or in a community facility. Lines of communication will vary from locality to locality and across local boundaries. It is for all involved in each locality to put these into place and ensure that they are known and maintained.

Voluntary Sector

9.60 The Review Team acknowledges the important role that the voluntary sector plays in campaigning, and in caring for people with a learning disability through the provision of residential accommodation, respite care, day care, leisure activities and domiciliary assistance. Many of the voluntary bodies involved in the field of learning disability were born out of carers' needs for information and services. The Review Team believes that the collective wisdom and knowledge of the voluntary organisations has much to offer policy makers, purchasers and providers. It recognises the importance of the statutory and voluntary sectors working in partnership, and that through a shared vision of the future they can utilise existing resources to the full. The voluntary organisations also have a part to play either directly, or by training advocates in ensuring that the rights of individual people with a learning disability are represented and protected.

Inter-Agency Co-operation

9.61 Whilst the Department and health and personal social services purchasers and providers, have a keen interest in ensuring the fullest development of individual potential, other Government Departments and agencies have a lead role to play in many aspects such as housing, further education, training for and support in employment, and leisure. Some policy issues are of common interest. These matters can best be addressed through co-operation. An exchange of information and a recognition of shared objectives at the policy making and implementation levels are essential. **Good liaison arrangements between all of the agencies involved are necessary both at the strategic planning level and at the point of service delivery to ensure the development and implementation of compatable and co-ordinated strategies.**

9.62 The Review Team recommends that **the remit of the Departmental Policy Forum on Disability established under the auspices of the Social Steering Group to co-ordinate disability policy and its presentation in Northern Ireland should be extended.** In future the Policy Forum should act to ensure that lead responsibilities are clearly recognised or assigned, and issues are handled in a consistent manner, to enable opportunities for people with a learning disability to be exploited to the maximum extent possible with a view to minimising the difficulties which often frustrate inclusion.

SECTION 10 – FINAL COMMENT

10.1 In the dynamic health and social care world, policies will continue to evolve as new pressures emerge with clinical interventions and care possibilities becoming increasingly sophisticated. In that sense no document can provide the final word.

10.2 Nevertheless, and in keeping with its remit, the Review Team believes that in addition to evaluating policy since 1978, the Report sets the policy direction for people with a learning disability in Northern Ireland for the foreseeable future. It establishes the core values which should underpin the development of services, and makes suggestions and recommendations the implementation of which the Review Team is confident will result in more flexible, responsive, and largely community based services to meet the needs of those in the population with a learning disability.

10.3 The challenge is for all Government Departments, and purchasers and providers of services, having regard to existing provision, assessed local need and available resources to ensure that the Review Team's findings and recommendations are taken fully into account.

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The Location of Board Residents (1) with a Mental Handicap at 31 March 1993

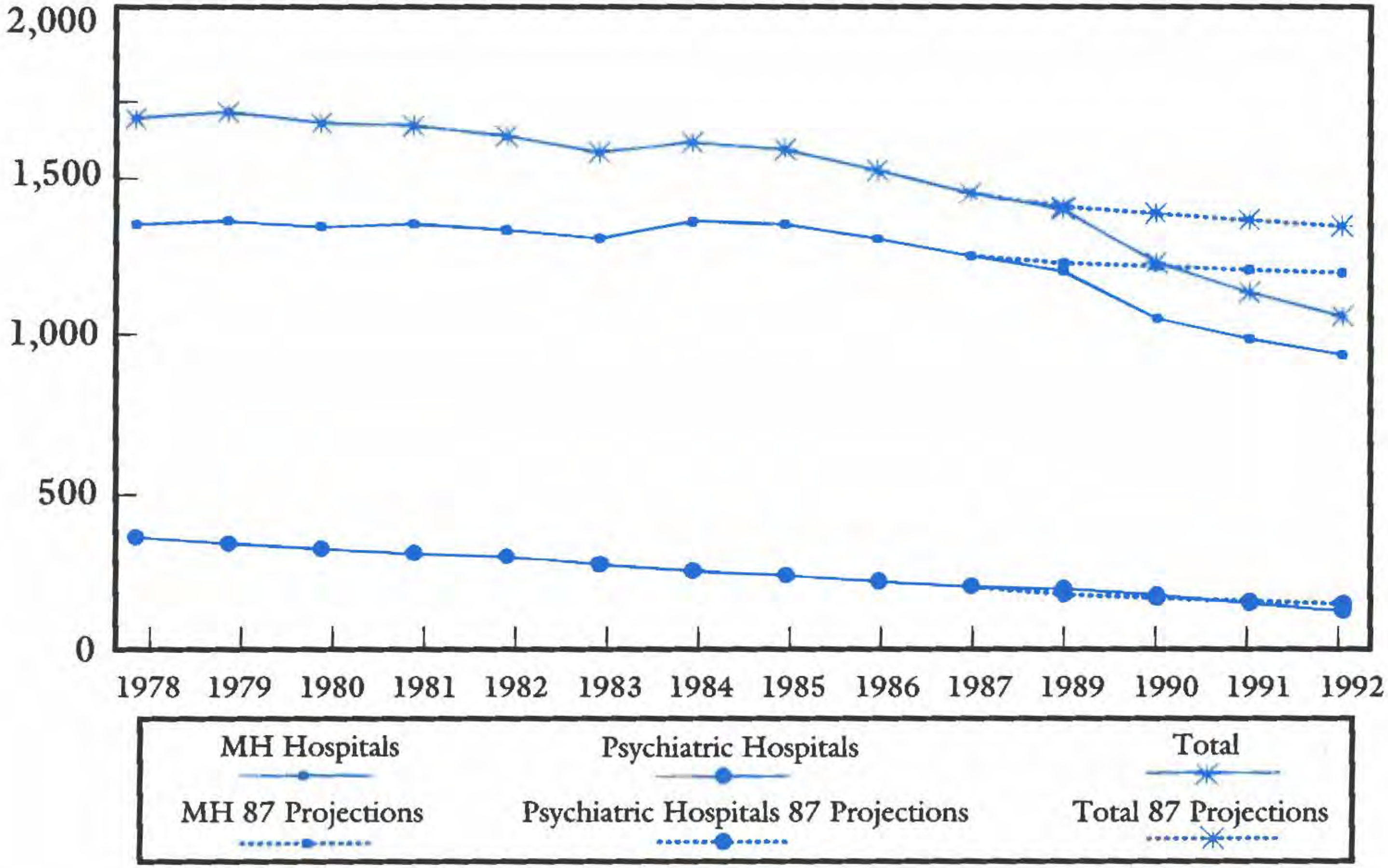
	Hospital (2)	Living in the Community (3)	Community Accommodation (4)	Others (5)	Total
Eastern Board	346	2,186	650	7	3,189
Northern Board	157	1,615	375	14	2,161
Southern Board	197	1,093	261	10	1,561
Western Board	103	1,033	185	26	1,347
Total	803	5,927	1,471	57	8,258

(1) Known to Units of Management
(2) Long stay patients in mental handicap and psychiatric hospitals
(3) Living independently or with family and friends
(4) In statutory, voluntary and private accommodation
(5) Includes those outside Northern Ireland and in foster care

Source: Units of Management

Table 1

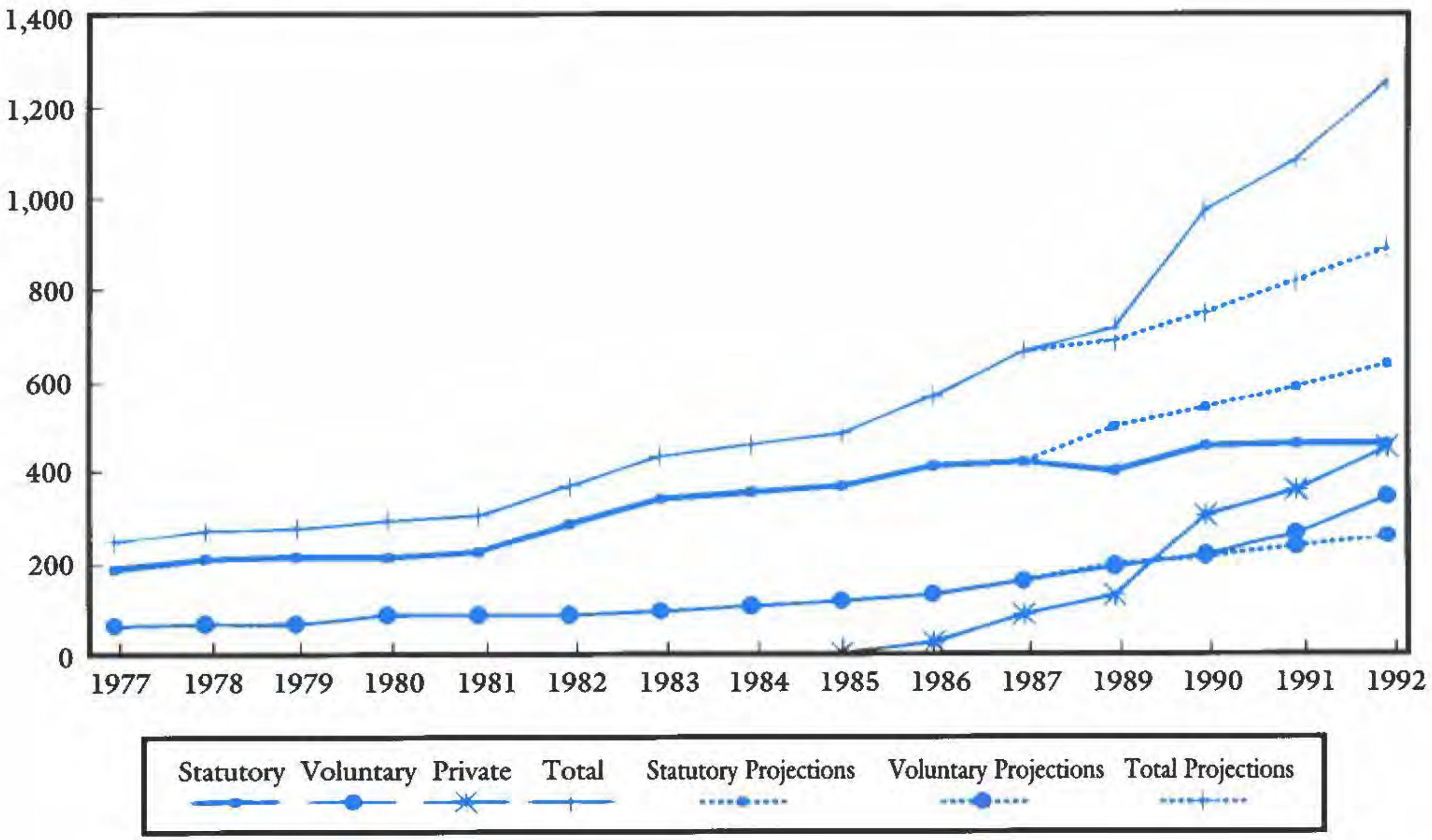
The Number of People with a Mental Handicap in Mental Handicap and Psychiatric Hospitals in Northern Ireland 1978–1992



Source: RIB
Figures are at 31 December to 1987 and at 31 March thereafter

Table 2

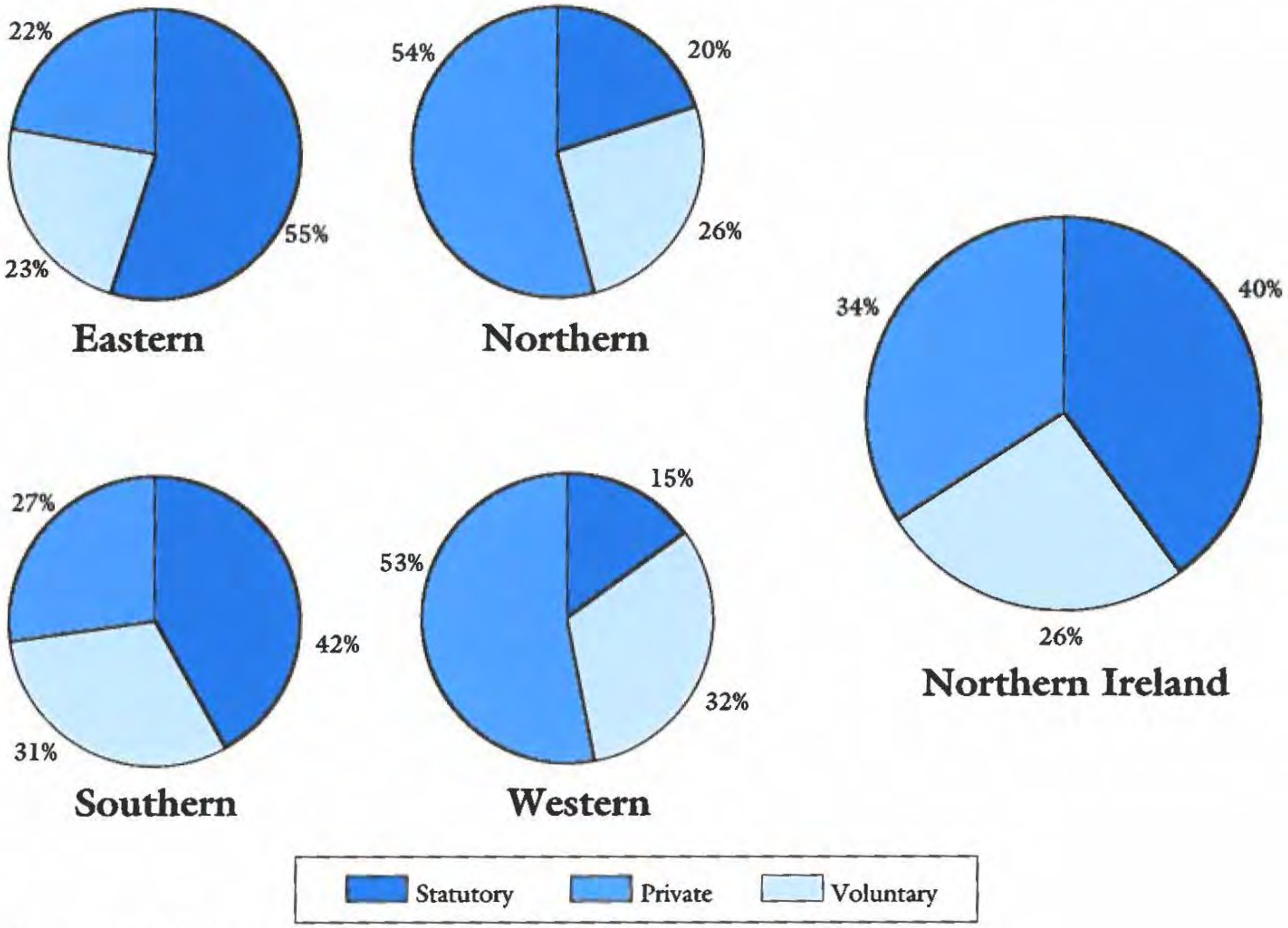
The Growth in Residential and Nursing Home Places provided by the Statutory, Private and Voluntary Sectors 1977–1992



Source: Statutory Homes – RIB (1992 figures are provisional)
Private and Voluntary Homes – Mental Handicap Branch
Figures are at 31 December to 1987 and at 31 March thereafter

Table 3

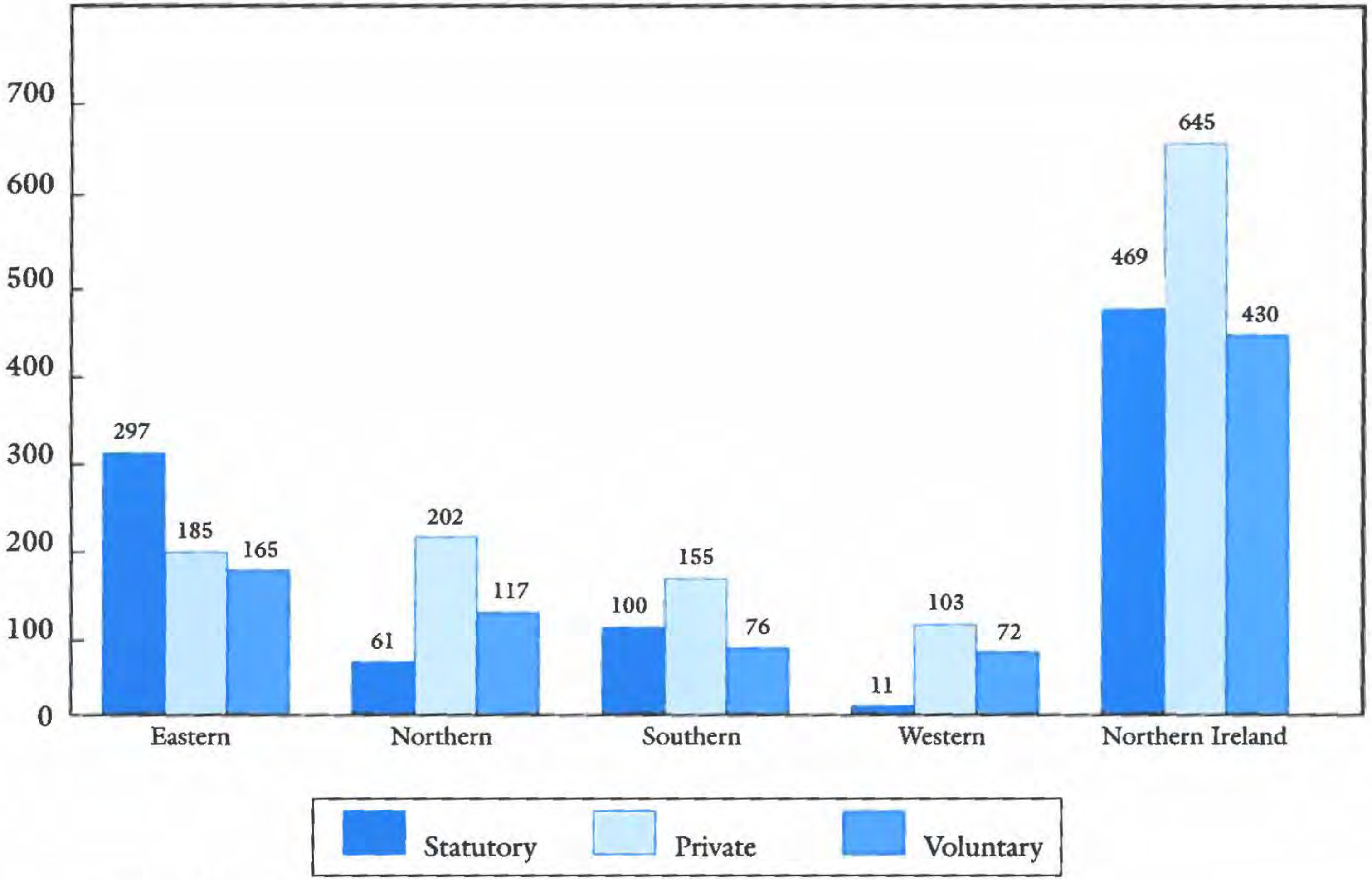
The Percentage of Residential and Nursing Home Places provided by the Statutory, Private and Voluntary Sectors at 31 March 1992



Source: Mental Handicap Branch

Table 4

The Number of Places available in Statutory, Private and Voluntary Sector Homes at 31 March 1993



Source: Mental Handicap Branch

Table 5

Capital Expenditure on Statutory Residential Accommodation for People with a Mental Handicap 1977–1992

	Eastern	Northern	Southern	Western	Total
1977/78	£1,735	£86,977	£0	£0	£88,712
1978/79	N/A	N/A	N/A	N/A	N/A
1979/80	£11,027	£3,755	£0	£9,200	£23,982
1980/81	£57,669	£40,136	£153,981	£105,293	£357,079
1981/82	£267,784	£1,723	£163,869	£17,114	£450,490
1982/83	£313,066	£52,459	£43,978	£0	£409,503
1983/84	£341,266	£22,209	£11,450	£84	£375,009
1984/85	£384,156	£166,504	£2,033	£622	£553,315
1985/86	£448,286	£281,525	£257,673	£0	£987,484
1986/87	£289,014	£42,559	£19,877	£3,826	£355,276
1987/88	£345,879	£38,054	£1,349	£0	£385,282
1988/89	£71,778	£3,554	£5,406	£0	£80,738
1989/90	£56,019	£657	£98,281	£792	£155,749
1990/91	£76,936	£11,075	£124,188	£520	£212,719
1991/92	£30,484	£17,867	£6,179	£822	£55,352
Total	**£2,695,099**	**£769,054**	**£888,264**	**£138,273**	**£4,490,690**

Source: Board Accounts
N/A: not available

Table 6

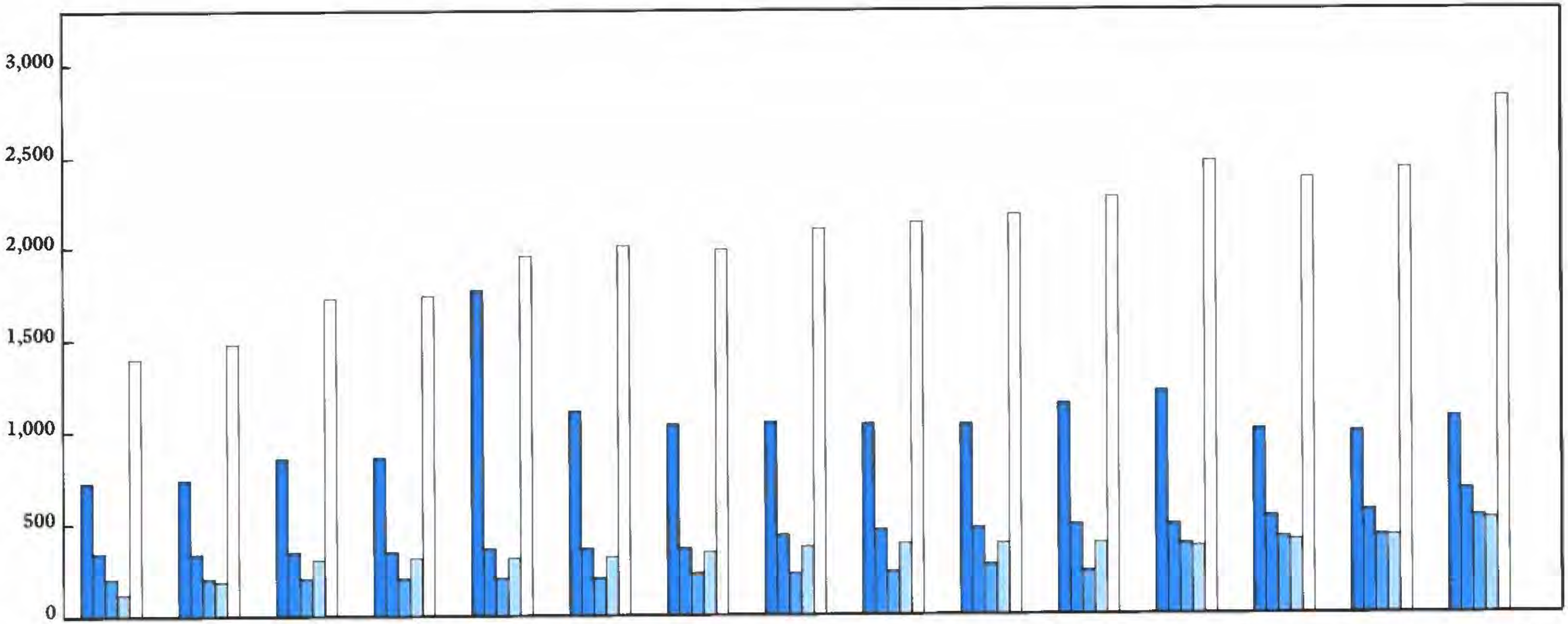
The Running Costs of Statutory Residential Accommodation for People with a Mental Handicap 1977–1992

	Running Costs (Actual)	Costs per Resident week (Actual)	Running Costs (91/92 Prices)	Cost per Resident week (91/92 Prices)
1977/78	£468,820	£47.81	£1,401,931	£142.97
1978/79	£576,076	£55.33	£1,553,603	£149.22
1979/80	£729,792	£67.68	£1,686,834	£156.43
1980/81	£931,907	£85.04	£1,820,308	£166.11
1981/82	£1,000,725	£100.42	£1,782,584	£178.88
1982/83	£1,439,831	£127.92	£2,394,211	£212.71
1983/84	£2,082,790	£147.32	£3,310,166	£234.13
1984/85	£2,395,512	£158.55	£3,622,906	£239.82
1985/86	£2,707,689	£171.18	£3,883,550	£245.52
1986/87	£3,131,965	£183.66	£4,352,066	£254.38
1987/88	£3,569,332	£197.17	£4,701,483	£259.71
1988/89	£3,909,265	£210.41	£4,799,706	£258.34
1989/90	£4,511,915	£244.89	£5,197,938	£282.12
1990/91	£5,057,679	£262.36	£5,394,742	£279.84
1991/92	£5,684,993	£280.42	£5,684,993	£280.42

Source: Analysis of Running Costs

Table 7

The Number of Statutory Day Care places in each Board



	1977	1978	1979	1980	1981	1982	1983	1984	1985	1986	1987	1989	1990	1991	1992
Eastern 🟦	739	753	867	873	1,073	1,123	1,053	1,063	1,051	1,046	1,158	1,228	1,020	1,005	1,086
Northern 🟦	343	343	354	354	372	372	372	442	472	480	496	495	541	573	687
Southern 🟦	210	210	210	210	210	210	235	235	237	277	241	390	425	435	537
Western 🟦	122	190	311	320	320	325	350	379	393	393	393	374	407	433	524
N. Ireland ☐	1,414	1,496	1,742	1,757	1,975	2,030	2,010	2,119	2,153	2,196	2,288	2,487	2,393	2,446	2,834

Source: Figures to 1991 from RIB
Figures for 1992 from Mental Handicap Branch

Table 8

Table 9

Capital Expenditure on Statutory Day Care Facilities for People with a Mental Handicap 1977–1992

	Eastern	Northern	Southern	Western	Total
1977/78	£27,108	£33,849	£5,473	£4,903	£71,333
1978/79	N/A	N/A	N/A	N/A	N/A
1979/80	£148,369	£25,471	£142,221	£65,550	£381,611
1980/81	£348,662	£8,278	£47,548	£4,675	£409,163
1981/82	£313,559	£9,371	£11,638	£14,415	£348,983
1982/83	£62,423	£1,596	£18,654	£22,421	£105,094
1983/84	£58,287	£204,671	£29,191	£290,479	£582,628
1984/85	£39,257	£261,944	£180,939	£55,692	£537,832
1985/86	£304,903	£521,939	£76,807	£14,785	£918,434
1986/87	£599,902	£132,196	£77,311	£267,298	£1,076,707
1987/88	£926,301	£39,916	£14,753	£631,303	£1,612,273
1988/89	£673,559	£313,303	£242,255	£331,969	£1,561,086
1989/90	£202,796	£89,663	£112,472	£122,620	£527,551
1990/91	£335,118	£296,153	£95,865	£23,669	£750,805
1991/92	£1,166,929	£9,704	£130,235	£32,387	£1,339,255
Total	**£5,207,173**	**£1,948,054**	**£1,185,362**	**£1,882,166**	**£10,222,755**

Source: Board Accounts
N/A: not available

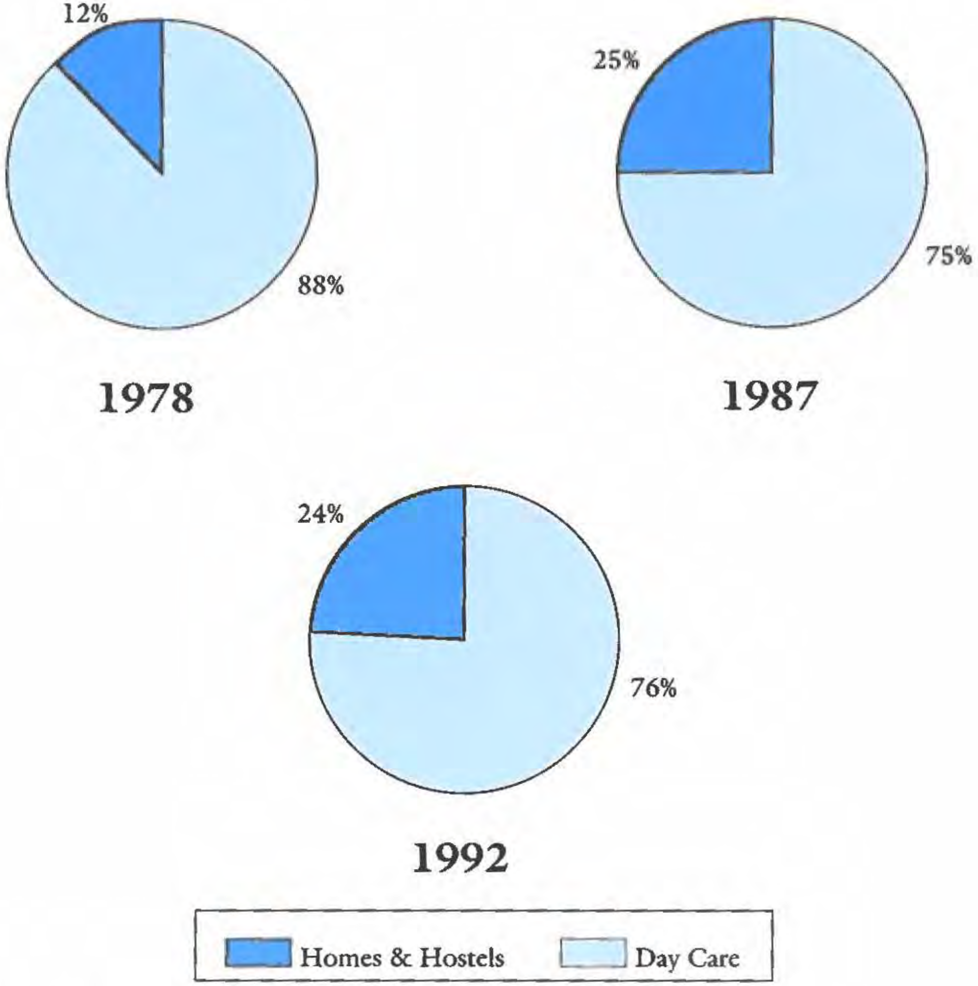
The Running Costs and Cost per Attendance at Statutory Day Care Facilities for People with a Mental Handicap 1977–1992

	Running Costs (Actual)	Costs per Attendance (Actual)	Running Costs (91/92 Prices)	Cost per Resident week (91/92 Prices)
1977/78	£908,613	£6.35	£2,717,062	£18.99
1978/79	£1,265,941	£7.28	£3,414,080	£19.63
1979/80	£1,649,376	£8.10	£3,812,352	£18.72
1980/81	£2,359,328	£10.27	£4,608,512	£20.06
1981/82	£2,774,740	£11.78	£4,942,624	£20.98
1982/83	£3,496,861	£13.01	£5,814,727	£21.63
1983/84	£3,729,082	£12.77	£5,926,609	£20.30
1984/85	£4,063,963	£13.08	£6,146,995	£19.78
1985/86	£4,593,609	£13.80	£6,588,464	£19.79
1986/87	£5,234,440	£15.36	£7,273,591	£21.34
1987/88	£7,084,538	£16.44	£9,331,583	£21.65
1988/89	£8,297,352	£18.07	£10,187,299	£22.19
1989/90	£9,225,695	£19.05	£10,628,435	£21.95
1990/91	£10,491,765	£21.08	£11,190,977	£22.48
1991/92	£11,832,859	£21.69	£11,832,859	£21.69

Source: Board Accounts (ABS15)

Table 10

Northern Board: Revenue expenditure on Mental Handicap Services*



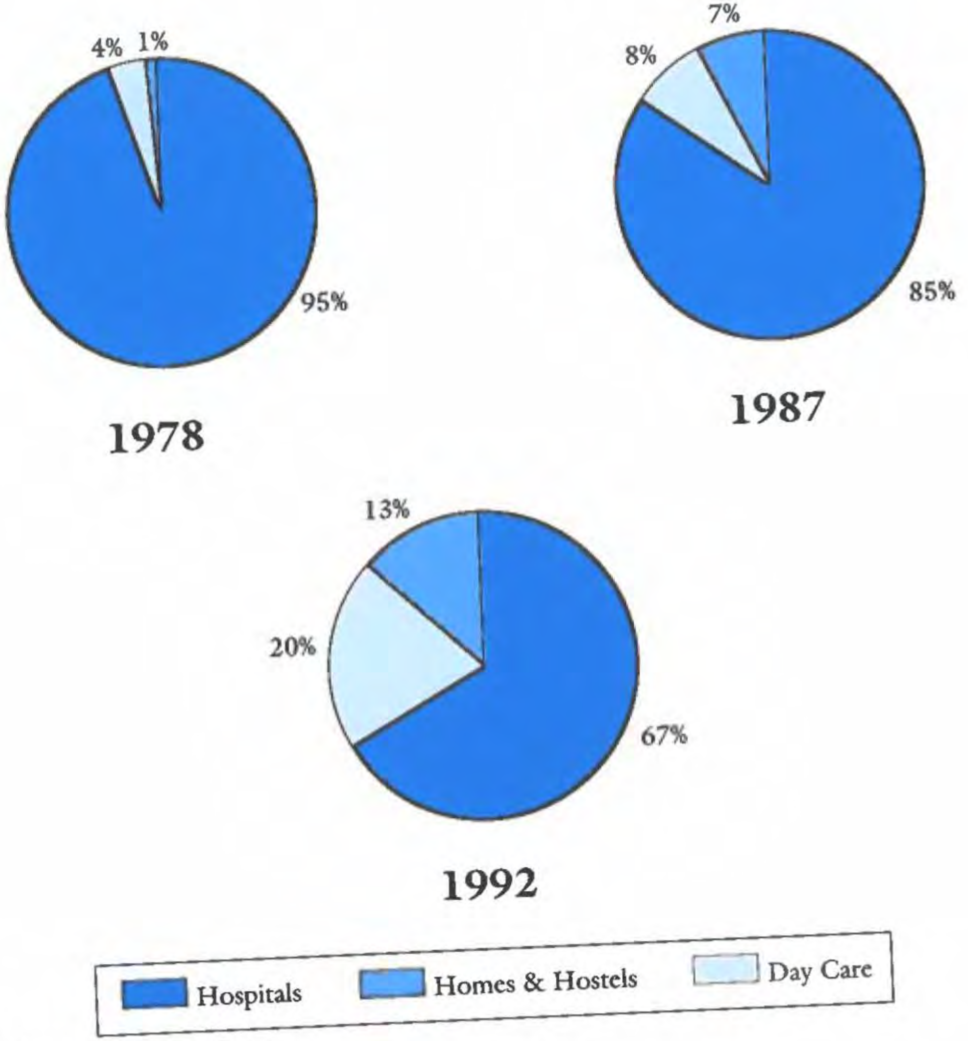
Source: Analysis of Running Costs

* excludes expenditure on domiciliary and community services

Table 13

Southern Board: Revenue expenditure on Mental Handicap Services*

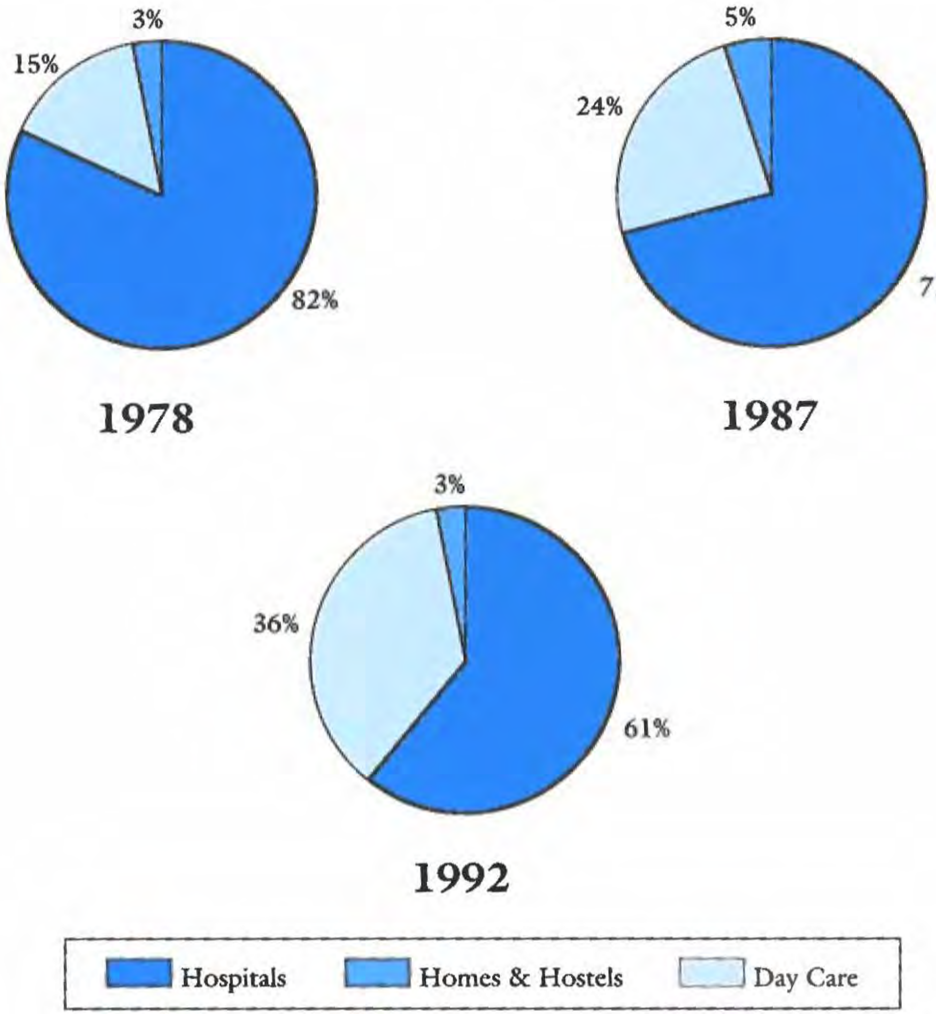
Table 14



Source: Analysis of Running Costs

* excludes expenditure on domiciliary and community services

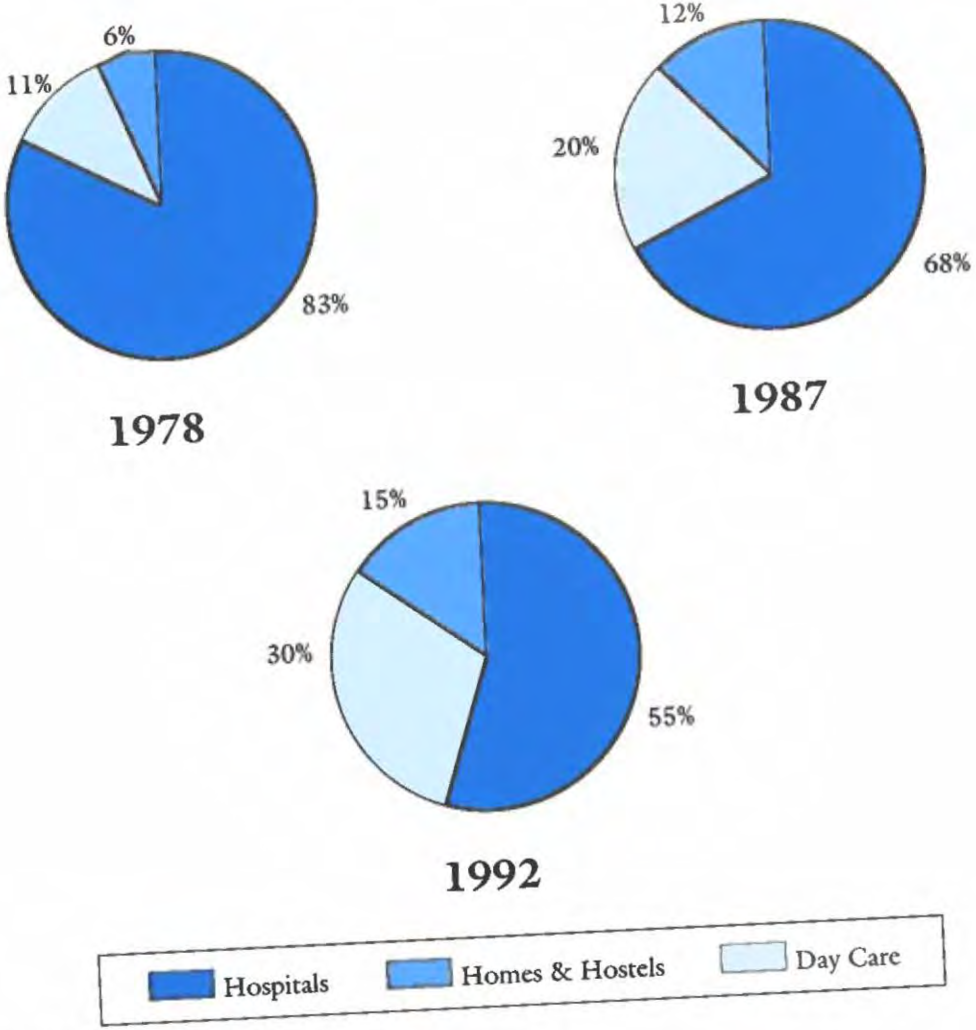
Western Board: Revenue expenditure on Mental Handicap Services*



Source: Analysis of Running Costs
* excludes expenditure on domiciliary and community services

Table 15

Northern Ireland: Revenue expenditure on Mental Handicap Services*



Source: Analysis of Running Costs

* excludes expenditure on domiciliary and community services

Table 16

ANNEXES

ANNEX 1

REVIEW TEAM MEMBERSHIP

CORE TEAM

W B Turner	Mental Handicap Branch
Dr H Kilgore	Medical Group
J Hilman	Nursing and Midwifery Group
Miss F M Beagon	Social Services Inspectorate (to 5 October 1994)
J S Fitzpatrick	Social Services Inspectorate (from 6 October 1994)
M Finlay	Mental Handicap Branch (to 14 January 1994)
C J McMinn	Mental Handicap Branch (from 17 January 1994)

ADVISORS

Miss M McCann	Client Groups Division
Miss M Boyd	Strategic Planning Branch
Mrs M T Foley	Economics Branch (to 19 February 1994)
G Campbell	Economics Branch (from 21 February 1994)
P Treacy	Purchasing and Performance Review Directorate
Dr L McWhirter	Research Management Branch

ANNEX 2

KEY POLICY AIMS AND OBJECTIVES

References

POLICY STATEMENT	1978
BAIRD REPORT 'YOU AND YOUR BABY'	1980
REGIONAL STRATEGY 1987 – 1992	1987
PEOPLE FIRST	1990
REGIONAL STRATEGY 1992 – 1997	1992

AIM 1. Prevention: preventive medicine and health education

OBJECTIVES	SUB OBJECTIVES
1.1 to reduce the incidence or severity of mental handicap (para 10-1978)	1.1.1 to improve health education (para 10-1978)
	1.1.2 to develop vaccination programmes (para 10-1978)
	1.1.3 to develop genetic counselling and chromosome testing services (paras 10 & 17-1978)
	1.1.4 improve maternal and child health services (para 10-1978)

KS AND TARGETS	OUTCOME	REFERENCE
specific tasks or targets set	prevention of mental handicap has not been a priority issue	Paras 3.4 to 3.7
increase uptake rates for asles and rubella munisations (1987)	uptake rates for vaccination have improved steadily	Paras 3.8 to 3.12
publicise the service (1980)	not done	Para 3.7
retain organisation of genetic ounselling on a regional asis (1980)	genetic counselling service retained as a regional basis	Para 3.14
o expand the service (1980)	additional clinics established	Para 3.16 and 3.17
o develop a genetic register 1980)	effective use of register being hindered by lack of support staff	Para 3.18
to expand antenatal diagnostic service to meet known need (1980)	service requires further development to enable counselling to be offered routinely	Para 3.19
to consider an antenatal screening programme for neural tube defects (1980)		
to ensure that all parents and prospective parents have access to genetic counselling services (1992)		
to introduce screening for hypothyroidism (1980)	all babies medically examined within 10 days of birth	Para 3.23
to medically examine all infants within 10 days of birth (1980)		
to provide a medical genetic laboratory (1980)	laboratory established in 1989	Para 3.25 and 3.26
to improve child health services (1980)	reductions in mortality rates achieved	Para 3.27

AIM 2. **Normalisation**: integration rather than segregation

OBJECTIVES	SUB OBJECTIVES
2.1 to ensure that no one who is mentally handicapped is excluded from society, deprived of membership of the wider community or institutionalised for want of stimulation or for lack of suitable facilities for care and treatment (para 2 – 1978)	2.1.1 to rehabilitate those in hospital (para 14 – 1978) 2.1.2 to provide a better environment and better facilities for those who need inpatient medical and nursing care (para 72 – 1978) 2.1.3 to keep people out of hospital who need not go there if they could be supported in their own home or in residential care (para 14 – 1978)

TASKS AND TARGETS	OUTCOME	REFERENCE
to reduce the existing hospital population (1978)	population reduced by 11%	Para 4.2 and 4.3
to reduce by 20% the number of mentally handicapped people in hospital (1987)	28% reduction achieved	Para 4.6
to reduce to a minimum the number of mentally handicapped people in psychiatric hospitals (1987)	44% reduction achieved	Para 4.6
to reduce to a minimum the number of mentally handicapped children in hospital (1987)	74% reduction achieved	Para 4.6
to reduce the number of people in mental handicap hospitals to less than 700 (1992)	on target	Para 4.10
to ensure that by 1997 no child with a mental handicap is receiving continuing care in hospital (1992)	on target	Para 4.10
to transfer patients nearer to home (para 74-1978)	the number of patients being treated outside their Board area has fallen	Para 4.19
to create additional hospital beds for mentally handicapped people (para 74 – 1978)	deficiencies eliminated	Para 4.13
to develop facilities in Muckamore Abbey Hospital (para 74 – 1978)	facilities improved	Para 4.17
to provide 525 places in 35 new residential homes (para 64 – 1978)	target achieved and exceeded	Para 5.10
to provide arrangements for respite care to assist families caring for mentally handicapped relatives (1987)	remains patchy at local levels	Para 5.41 to 5.46

OBJECTIVES	SUB OBJECTIVES
2.1 contd.	2.1.4 to undertake comprehensive assessment (paras 16(i) & 18 – 1978) 2.1.5 to establish guidelines for maintaining and renewing the District Register to a consistent set of criteria (para 21 – 1978) 2.1.6 to charge residents in homes for mentally handicapped people on the same basis as for people in residential accommodation (para 36 & 37 – 1978) 2.1.7 to expand day care facilities (paras 62 to 67 – 1978) 2.1.8 to develop the day hospital concept (para 74 – 1978)

TASKS AND TARGETS	OUTCOME	REFERENCE
to establish guidelines for the operation of multi-disciplinary assessment (1978)	implemented	Para 5.3
to fully assess the needs of each individual by a multi-disciplinary team (1987)	implemented	Para 5.3
to make proper assessment of need the cornerstone of high quality care (1990)	comprehensive assessment arrangements in place	Para 5.3
to provide co-ordinated advice and support for the families of mentally handicapped people (paras 16(iii) & 23-25-1978)	carer's needs identified as part of clients' assessment	Para 5.5
to ensure that service providers make practical support for carers a high priority (1990)		
	Register discontinued by Mental Health (NI) Order 1986	Para 2.11
to decide how this could best be done in light of the Review of Supplementary Benefit (1978)	charging implemented and revised in line with current social security legislation	Para 5.22 to 5.25
to provide 700 places in 10 new adult training centres (1978)	target met and exceeded	Para 5.31
to issue guidance for the development of the day hospital concept (1978)	priority given to alternative day-care facilities	Para 5.36

OBJECTIVES	SUB OBJECTIVES
2.2 to meet the needs of the mentally handicapped person where these are the same as for other members of the wider community, not by removal from society but as part of the general provision for children, the elderly, or any other group (para 2 – 1978)	2.2.1 to develop foster care for children with a mental handicap as part of general child care provision (para 26 – 1978) 2.2.2 to set up with the DENI an interdepartmental working party to study the needs of mentally handicapped children for education, social training and care (paras 51 & 54 – 1978) 2.2.3 to integrate services for mentally handicapped people with the management arrangements for other services (paras 51 – 1978) 2.2.4 to ensure that mentally handicapped people receive adequate dental care (para 70 – 1978)
2.3 to develop the effectiveness of the voluntary sector (para 55 – 1978)	2.3.1 to encourage voluntary activity (para 56 – 1978) 2.3.2 to consult voluntary organisations (para 59 – 1978)

TASKS AND TARGETS	OUTCOME	REFERENCE
	foster care is an accepted form of care for children with a mental handicap	Para 6.8
	responsibility transferred to DENI	Para 7.4
to bring responsibility for the management of mental handicap services within the District Executive Team (para 54 – 1978)	management integrated	Para 1.8
	necessary services are in place	Para 6.5
to give volunteers jobs which are clearly defined (para 58 – 1978)		
to co-operate with parents and voluntary groups in the running of certain activities and facilities (para 59 – 1978)	voluntary activity encouraged by financial support and through consultation.	
to provide volunteers with adequate preparation and continuing support (para 58 – 1978)	guidance to Boards on support for voluntary organisation is currently being revised.	Para 6.9 to 6.13
to adopt policies which encourage and incorporate voluntary effort (para 59 – 1978)	the Department has established a Voluntary Activity Unit to co-ordinate support for the voluntary sector.	
to consult voluntary organisations at an early stage in the planning of facilities (para 59 – 1978)		
to give voluntary organisations access to discussion at Board level (para 59 – 1978)		
to appoint an identifiable liaison officer (para 59 – 1978)		

OBJECTIVES	SUB OBJECTIVES
2.4 to ensure the availability of trained staff (para 70 – 1978)	2.4.1 to develop in-service training (para 70 – 1978) 2.4.2 to expand recruitment and training in line with the development programme (para 70 – 1978)

TASKS AND TARGETS	OUTCOME	REFERENCE
to establish CSS courses in NI (para 70 – 1978)	Boards have co-operated fully in pursuit of these recommendations	Para 5.58
to encourage nursing personnel to take advantage of CQSW (para 70 – 1978)		
to review the organisation of psychological services (para 70 – 1978)	review undertaken and annual intake monitored by the Department	Para 5.50
to have specific regard to mental handicap in future manpower planning and training (para 70 – 1978)	a manpower planning methodology has recently been devised by the Department	Para 5.52
to review the requirements for trained therapeutic paramedical staff (para 70 – 1978)	recruitment kept under review	Para 5.56

ANNEX 3

RELATED RESEARCH

A study of the longer term needs for specialist treatment and care services for people with a mental handicap – carried out by the Eastern Health and Social Services Board (the Inpatient Needs Review) – Report 'Future Provision for Treatment and Care Services for People with a Mental Handicap' – 1994.

An evaluation study of the effects of care in the community for people discharged from psychiatric and mental handicap hospitals Northern Ireland – carried out for the Department by the Health and Health Care Research Unit, QUB (the HHCRU Study) – Report 'Opening New Doors' – 1994.

'Inspection of Day Services for Adults with a Mental Handicap/Learning Difficulty in Northern Ireland' (the SSI Report on Day Services) – 1992.

A study to quantify the availability of and the demand for respite care for people with mental handicaps/learning difficulties in Northern Ireland – carried out for the Department by Mencap (the Respite Care Review) – Report 'Provision of Respite Care for People with a Mental Handicap see (Learning Difficulty) in Northern Ireland 1992–1993' – 1994.

A literature review on work carried out between 1978 and 1993 relevant to mental handicap in Northern Ireland -undertaken for the Department by the Centre for Health and Social Research, University of Ulster (the Literature Review) – Report 'A Review of the Literature on Mental Handicap in Northern Ireland' – 1995.

A study of the impact of the caring task on the lifestyles of aging mothers and other carers with primary responsibility for an adult with mental handicap by Institute for Counselling and Personal Development – Report 'The Burden of Care' – 1993.

ANNEX 4

RESPONDENTS

Department of Education for Northern Ireland
Professor Sines, University of Ulster at Jordanstown
Southern Health and Social Services Council
Central Nursing Advisory Committee
Parents and Professionals and Autism (PAPA)
Dr G J Calvert, Regional Advisor on the psychiatry of mental handicap to the Royal College of Psychiatrists
Craigavon Area Hospital Group Health and Social Services Trust
Central Council for Education and Training in Social Work (CCETSW)
Families-in-Contact
North and West Belfast Health and Social Services Trust
Newry and Mourne Health and Social Services Trust
Northern Ireland Federation of Housing Associations
Dr O E P Shanks, Muckamore Abbey Hospital
Central Personal Social Services Advisory Committee (CPSSAC)
The Orchardville Society
Western Health and Social Services Council
Department of Economic Development
Dr C M Marriott, Muckamore Abbey Hospital
Armagh and Dungannon Unit of Management
British Medical Association, Northern Ireland Office
Institute for Counselling and Personal Development
Southern Health and Social Services Board, Area Medical Advisory Committee
Dr M G McGinnity, Muckamore Abbey Hospital
The National Board for Nursing, Midwifery and Health Visiting for Northern Ireland
Speech and Language Therapy Service for Children and Adults with Severe Learning Difficulties
Homefirst Community Unit
The Queen's University of Belfast, School of Clinical Medicine
Northern Ireland Section Royal College of Psychiatrists
Disability Action
Northern Health and Social Services Council
Causeway Unit of Management
Eastern Health and Social Services Board
Carers National Association
Northern Ireland Council for Postgraduate Medical and Dental Education
LEAD – Northern Ireland Coalition on Mental HandicapWestern Health and Social Services Board
Royal Society for Mentally Handicapped Children and Adults (Mencap)
Northern Ireland Public Service Alliance (NIPSA)
South and East Belfast Health and Social Services Trust

Northern Health and Social Services Board
Southern Health and Social Services Board
Profoundly Handicapped Children's Association
North Down and Ards Community Health and Social Services Trust
Mental Health Commission for Northern Ireland
The Sandown Group
Bryson House
Dr R W McVicker, Muckamore Abbey Hospital
UNISON Northern Ireland
Down's Syndrome Association
Health Promotion Agency
Down Lisburn Health and Social Services Trust
Craigavon and Banbridge Community Health and Social Services Trust
Department of the Environment for Northern Ireland

ANNEX 5

1978 GENERAL PRINCIPLES

1. A family with a handicapped member has the same needs for general social services as all other families. The family and the handicapped child or adult also need special additional help, which varies according to the severity of the handicap, whether there are associated physical disabilities or behaviour problems, the age of the handicapped person and his family situation.

2. Mentally handicapped children and adults should not be segregated unnecessarily from other people of similar age, nor from the general life of the local community.

3. Full use should be made of available knowledge which can help to prevent mental handicap or to reduce the severity of its effects.

4. There should be a comprehensive initial assessment and periodic reassessment of the needs of each handicapped person and his family.

5. Handicapped persons need stimulation, social training and education and purposeful occupation or employment in order to develop to their maximum capacity and to exercise all the skills they acquire, however limited these may be.

6. Each handicapped person should live with his own family as long as this does not impose an undue burden on them or him, and he and his family should receive full advice and support. If he has to leave home for a foster home, residential home or hospital, temporarily or permanently, links with his own family should normally be maintained.

7. The range of services should be such that the family can be sure that their handicapped member will be adequately cared for when it becomes necessary for him to leave the family home.

8. When a handicapped person has to leave his family home, temporarily or permanently, the substitute home should be as homelike as possible, even if it is a hospital. It should provide sympathetic and constant human relationships.

9. There should be proper co-ordination in the application of relevant professional skills for the benefit of individual handicapped people and their families, and in the planning and administration of relevant services, whether or not these cross administrative frontiers.

10. Personal social services for the mentally handicapped should develop as an integral part of personal social services generally.

11. Hospital services for the long-term care of the mentally handicapped should preferably be easily accessible to the population they serve. There should be adequate links with other hospital services, so that a full range of specialist skills is easily available when needed for assessment or treatment.

12. Health and personal social services for the mentally handicapped should be planned and operated on a co-ordinated basis through a programme of care.

13. There should be close collaboration between these services and education and employment services.

14. Voluntary service can make a major contribution to the welfare of mentally handicapped people and their families at all stages of their lives and wherever they are living, and should be fully enabled to do so.

15. Understanding and help from friends and neighbours and from the community at large are needed to help the family to maintain a normal social life and to give the handicapped member as nearly normal a life as his handicap or handicaps permit.

ANNEX 6

1994 GENERAL PRINCIPLES

1. Everyone should have the opportunity to access available knowledge and to make informed decisions which can help to prevent learning disability or to reduce the severity of its effects.

2. The family and principal carer of a person with a learning disability are entitled to expect information and support designed to ensure that the person's full potential is realised.

3. A person with a learning disability is a citizen who should enjoy, and be enabled to enjoy the rights, services, and status of a citizen.

4. A person with a learning disability is entitled to acceptance by society, respect as an individual and to recognition of his or her individuality.

5. A person with a learning disability has the same needs for services as other members of society and is also entitled to expect support in accessing those services.

6. A person with a learning disability is entitled to expect additional support based on regular and comprehensive assessment of need.

7. A person with a learning disability has a right to express needs, preferences and choice in the determination of his or her lifestyle.

8. Support for people with a learning disability should be designed to help them maximise their potential and exercise their skills to the full.

9. Service purchasers and providers should recognise the need for co-operation, and demonstrate a willingness to co-operate, for the benefit of people with a learning disability.

10. A family with a member who has a learning disability has the same needs for general social services as all other families.

11. The family and principal carer of a child or adult with a learning disability also are entitled to expect additional support according to assessed needs.

12. Where a person with a learning disability is living away from home the support and range of services provided should be such that the family can be sure that he or she is receiving, and will continue to receive adequate, care.

ANNEX 7

SERVICE PRINCIPLES

1. Services should be based upon the assessed needs of individuals, rather than the ability of individuals to fit into existing models of provision.

2. Services should respond flexibly and sensitively to the needs of individuals and their carers.

3. Services should be local and accessible.

4. Services should be prompt, effective, equitable and comprehensive.

5. Services should concentrate on those with greatest needs.

6. The quality of services should be measured by the extent to which they provide:

    privacy – the right of individuals to be free from intrusion or public attention into their affairs;

    dignity – a recognition of the intrinsic value of people regardless of circumstances by respecting their uniqueness and their personal needs, treating with respect;

    independence – opportunities to think and act without reference to another person including a willingness to incur a degree of calculated risk;

    choice – opportunity to select independently from a range of options;

    rights – the maintenance of all entitlements associated with citizenship; and

    fulfilment – the realisation of personal aspirations and abilities in all aspects of daily life.

ANNEX 8

ROYAL COLLEGE OF PHYSICIANS RECOMMENDATIONS ON PRENATAL DIAGNOSIS AND GENETIC SCREENING

Equity in health care

1. Genetic screening and prenatal diagnosis services should be equally available to the whole community. They should be recognised as an intrinsic component of maternal and child health services.

Policy advisory structure

2. A policy advisory structure be set up to facilitate decision making in the future.

Code of practice

3. Although there is majority support for the principles of prenatal diagnosis, some serious ethical issues are involved. A professional code of practice governing genetic screening should be developed. It should be widely publicised to reassure the public that:

   (a) prenatal diagnosis will not be used for a positive eugenic policy;

   (b) prevention programmes will not detract the appreciation of, and provision for people with disabilities.

Resources

4. Resources should be made available:

   (a) to ensure equitable delivery of existing services;

   (b) to support the development, evaluation and early application of new approaches.

Professional training

5. Professional training in medical genetics and the principles of genetic counselling should be provided for all maternal and child health workers (GPs, obstetricians, paediatricians, family planners, health visitors and midwives). Official contact should be made with the relevant professional bodies to develop the genetic component of the training curriculum and to organise updating courses for existing practitioners.

Information and counselling

6. Because of the large numbers involved, and the relative simplicity of some issues in large-scale screening programmes, genetic information and counselling must be provided at the community level. The ideal professionals to provide information and counselling would be specially trained health visitors and midwives, who are already the point of first and most frequent contact with mother and child. The suggestion is consistent with current proposals to train nurse specialists, who in this case would act as reference and training resources for MCH workers in general.

Specialist genetic counsellors

7. Specialist genetic counsellors already work with clinical geneticists and with specialists in particular disorders. Equivalent specialist counsellors should be attached to each obstetric unit practising prenatal diagnosis. It is urgent to define a career structure for such specialist counsellors, who may have differing professional backgrounds, and carry out a wide range of activities.

National organisation

8. (a) Policy formulation, defining a career structure for genetic counsellors, development and distribution of educational materials and service monitoring, should be organised at national level.

(b) Each region needs to develop an organisation for ensuring delivery of genetic screening and prenatal diagnosis. This organisation should include clinical genetics and foetal medicine centres, neonatologists and paediatric consultants, primary care physicians, community physicians, health workers involved in family-planning, health visitors, midwives, nurses, and experts in health education and community medicine.

District organisation

(c) For the service to be delivered effectively, the regional organisation must have roots at the district level, in the antenatal clinics and among general practitioners and other maternal and child health workers.

District and regional co-ordinator

9. Because of their multi-disciplinary nature, prenatal diagnosis services should be under the overall supervision of designated district and regional co-ordinators who may often, but not always, be clinical geneticists. The co-ordinator's responsibility should be to ensure that the services are provided to the recommended standard and co-ordinated and monitored throughout each region.

National audit

10. Though monitoring should be organised on a regional basis, a national centre is needed to develop appropriate methods, co-ordinate information nationally, and stimulate equal service delivery throughout the country.

Genetic health education

11. Face-to-face counselling and written information are complementary rather than alternative sources of information for an educated population; one should not be given one without the other. Information packages need to be directed to schools, young couples and pregnant women, and individuals with defined genetic risks. Because of the wide range and different levels of educational resources needed to cover the spectrum of potential abnormalities, a National Genetic Health Education Unit is needed to generate, store and disseminate information.

Implementation

12. These proposals should be implemented through working groups and supported by the DoH.

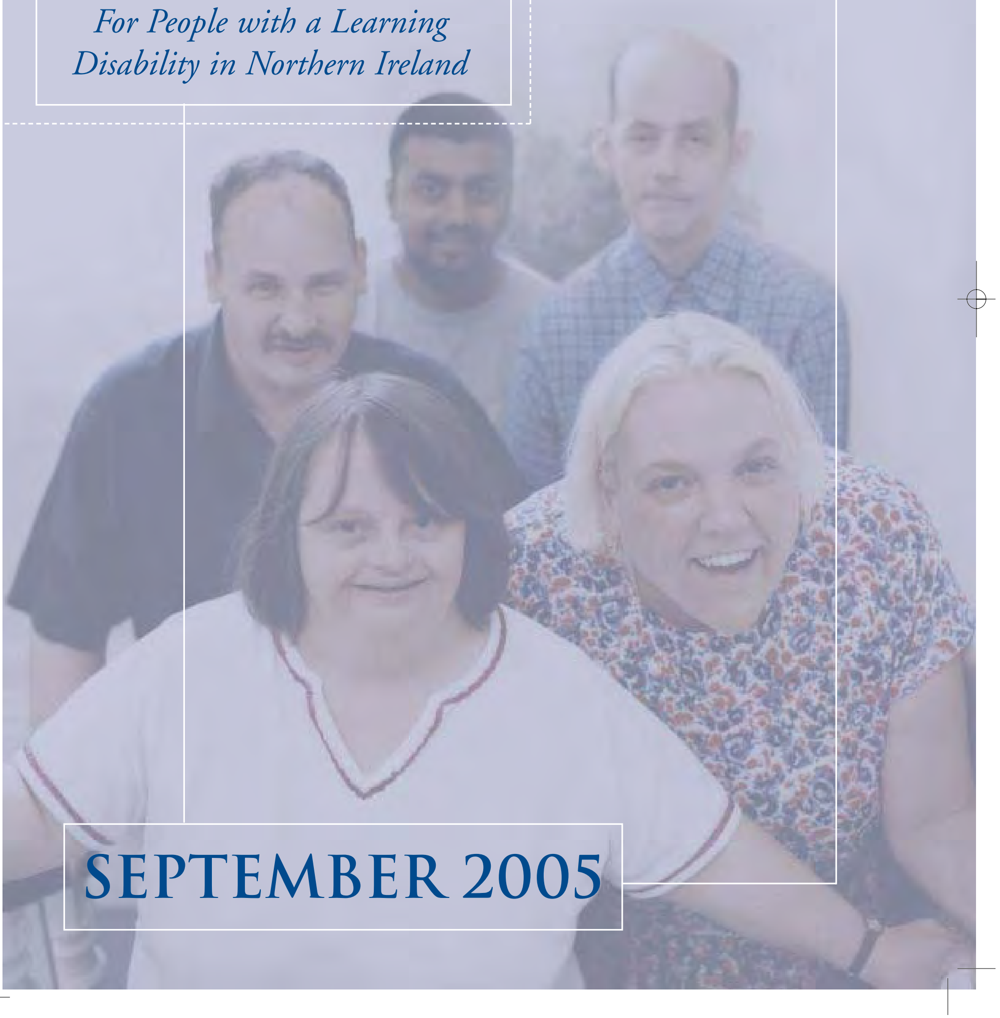
MMcG- 37

REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY

(NORTHERN IRELAND)

EQUAL LIVES:

Review of Policy and Services
For People with a Learning
Disability in Northern Ireland



SEPTEMBER 2005

EQUAL LIVES[1]

Explanation

Figures in bold in brackets refer to references to show where we got the information from. The details are given in Annex E at the back of the report.

Words that are underlined refer to words that are explained in the Glossary at Annex D.

The Glossary also lists all abbreviations that are used in this report.

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E-mail: mentalhealth.reviewteam@dhsspsni.gov.uk
Photographs: Mencap
September 2005

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[1] During the Review we met every month with the Equal Lives Group; men and women with a learning disability who advised us on the work. They said that the Review should focus on ensuring that people with a learning disability have equal chances and choices to other people in Northern Ireland. We have called this report *Equal Lives* to reflect their priorities.

CONTENTS

FOREWORD

In the summer of 2002, I was invited to chair the independent Review of Mental Health and Learning Disability, commencing in October of that year. By March 2003 it was clear that the work consisted of several interlinked reviews under one overarching title, and encompassing policy, services and legislation.

The Review Steering Committee has presided over the work of 10 major Expert Working Committees. In consultation with Government, we agreed to produce our reports on a phased basis.

Equal Lives is the second report from the Review. It sets out a compelling vision for developing services for men, women and children with a learning disability for the next 15 to 20 years.

The Equal Lives Review has adopted an evidence-based approach, drawing upon existing relevant information and research, and where necessary commissioning research. Exemplars of best practice local, national and international, have informed the debate. Widespread consultations with stakeholders, in particular people with a learning disability and their families and carers, have endorsed our vision and the strategic direction of the Equal Lives Review.

The Equal Lives Review has concluded that progress needs to be accelerated on establishing a new service model, which draws a line under outdated notions of grouping people with a learning disability together and their segregation in services where they are required to lead separate lives from their neighbours. The model of the future needs to be based on integration, where people participate fully in the lives of their communities and are supported to individually access the full range of opportunities that are open to everyone else.

The success of implementing the Equal Lives recommendations depends on the contribution of many stakeholders, but most of all Government, who must give a lead on implementing the process of change. We fully recognise the resource implications and urge Government, in particular the Department of Health, Social Services and Public Safety, to begin the necessary process of reform and modernisation of these services immediately.

Professor Roy McClelland, deputy Chairman of the Review, and I thank Siobhan Bogues, who chaired the Learning Disability Working Committee, and all involved in the Equal Lives Review for their efforts and their commitment.

Professor David R Bamford
Chairman

20:20 VISION

Chapter 1

We hope the Review makes sure that people with a learning disability get the same chances and choices as everyone else. **Equal Lives Group**

Show us respect by giving us the support and information we need. **Family Carer**

About the Review of Mental Health and Learning Disability (Northern Ireland)

1.1 In October 2002 the Department of Health, Social Services and Public Safety (DHSSPS) commissioned an independent review of law, policy and service provision affecting people with mental health needs or learning disability in Northern Ireland. The Review of Mental Health and Learning Disability (Northern Ireland) could be described as having 3 distinct strands:

- a review of policy and service provision for people with a learning disability
- a review of policy and service provision for people with mental health problems
- a review of the Mental Health (Northern Ireland) Order 1986.

1.2 While there are overlaps between each of these strands there are clear distinctions and in particular, the Review of Mental Health and Learning Disability (the Review) recognises that learning disability and mental health problems are very distinct and separate conditions.

1.3 This is reflected in the way in which the Review is being carried out. An overall Steering Committee, whose terms of reference are shown at Annex B, manages the Review. They are guided by inputs from Expert Working Committees[2], each of which is examining a particular area:

- Adult Mental Health
- Child and Adolescent Mental Health
- Forensic Issues
- Mental Health Promotion
- Dementia and Mental Health Issues of Older People
- Social Justice and Citizenship
- Legal Issues
- Needs and Resources

The areas being covered by each Working Committee are given at Annex C.

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[2] Words that are underlined refer to items that are explained in the Glossary at Annex D at the back of the report

1.4 This report summarises the findings of the Learning Disability Working Committee and presents a wide range of proposals for improving the lives of people with a learning disability and their families by developing responses that are based on the key values of:

- Citizenship
- Social Inclusion
- Empowerment
- Working Together
- Individual Support.

1.5 The Review Steering Committee agreed the following Terms of Reference for the Equal Lives Review:

Terms of Reference

- To carry out a review of policy and services for children and adults with a learning disability
- To take into account the evidence base, national and international, for best practice in the assessment of need, the planning of supports, effective means of delivering services and the empowerment of people with a learning disability
- To comprehensively research the significant issues for consideration in future policy, utilising all reliable, valid and up-to-date evidence and to take account of local initiatives and needs
- To work collaboratively and consult widely with all relevant stakeholders both within and outside the health and personal social services sector
- To liaise as necessary with colleagues on the other Expert Working Committees on interface issues
- To bring forward to the Steering Committee a comprehensive and prioritised set of recommendations giving due consideration to cost, workforce issues and infrastructure needs.

How Did We Carry Out the Equal Lives Review?

1.6 The Equal Lives Review is based on an extensive range of consultations, research and analysis, carried out over the last year that included:

- establishing a Learning Disability Working Committee that managed the Equal Lives Review
- setting up the Equal Lives Group, which was made up of 16 men and women with a learning disability from different parts of Northern Ireland who met with us every month and gave advice on issues that they felt should be addressed
- meeting on 6 occasions with a group of family carers who gave feedback on ideas coming out of the Equal Lives Review
- holding 6 public meetings with men and women with a learning disability who talked about what they thought needed to change to make their lives better. Their views were collected by Equal Lives Group members and published in a separate report called We Have a Dream... (1)
- holding 5 public meetings for carers in different parts of Northern Ireland to share their concerns and suggestions. The issues raised at these meetings were published in a separate report - Focus on Families. (2)
- meetings with a group of young people who told us about the specific things they want us to address
- consultation with men and women who have complex health needs and/or a profound learning disability and their carers. The issues raised at these meetings were published in a separate report called Challenges of Complexity. (3)[3]
- setting up 6 Task Groups with various stakeholders to examine issues identified by the Committee as being particularly significant in relation to improving the lives of people with a learning disability - refer to Annex F for membership of the Equal Lives Review groups:
    - Support for Children and Young People and Their Families
    - Accommodation and Support
    - Day Opportunities
    - Ageing
    - Mental Health
    - Physical Health
- setting up a free phone line to provide an opportunity for people to share their views in a confidential manner. This service was designed for those who could not, or were unwilling to, attend meetings and to ensure that people from all over Northern Ireland could have their voices heard.

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[3] These reports are available on the review web-site www.rmhldni.gov.uk

- inviting people to make presentations to the Learning Disability Working Committee and Task Groups. Men and women with a learning disability, family carers and staff from a wide range of agencies all took this opportunity to tell us what is working well and what needs to change.
- inviting individuals and organisations to provide written comments. Many people took this opportunity to express their concerns and ideas to the Learning Disability Working Committee.
- holding conferences and seminars on particular issues attended by over 400 people so that new developments in services nationally and internationally could be presented and recommendations for local services identified:
  - day opportunities
  - lessons from Sweden
  - physical and mental health
  - lessons from other reviews on implementation
  - staffing and workforce issues
  - growing older
  - education
  - youth
  - family support
  - play
  - promoting equality
  - early intervention
- finding out what has happened in other countries and locally by reading policy documents and commissioning research from the University of Ulster. This research focused on 4 areas:
  - creation of a directory of research studies into learning disability undertaken in Northern Ireland[4]
  - strategic review of learning disability policy and service provision
  - reports on the 6 topics studied by the Task Groups
  - study of organisational arrangements and how they may develop in the future.
- 2 seminars for political representatives
- circulation of a consultation report to a wide range of individuals and organisations which resulted in over 70 written responses

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[4] This directory is stored on a cd-rom and is available free-of-charge from Room 12J10, School of Nursing, University of Ulster, Newtownabbey, Northern Ireland BT37 OQB

- an independent facilitator was commissioned to run a series of meetings with family carers and men and women with a learning disability to secure feedback on the draft Equal Lives report
- detailed consideration of all responses received and redrafting to produce this final report.

How Does Our Work Fit in With the Rest of the Review of Mental Health and Learning Disability?

1.7 The fact that the Equal Lives Review was conducted within a wider review of legislation, policy and services relating to mental health and learning disability had a number of advantages. First, it has meant that we have been able to inform the work of other Expert Working Committees, which will also address the mental health issues affecting people with a learning disability. Second, we have been able to liaise with the Expert Working Committees that are concerned with learning disability and mental health matters in equal measure, i.e. Legal Issues, Social Justice and Citizenship, and Needs and Resources. Third, we have been able to contribute to the current Department of Health, Social Services and Public Safety review of workforce in learning disability and mental health along with Review colleagues from other Committees. These Committees will produce separate reports, each of which will highlight issues and actions to be taken which should contribute to an overall improvement in the lives of men, women and children with a learning disability in Northern Ireland, albeit within the broader context addressed by that Committee. The Learning Disability Working Committee has highlighted the factors that we believe should be considered by these committees in their work. This report provides the overall context in which further recommendations from the various Working Committees will be placed. Their reports will be produced during 2005 to 2006.

1.8 However, we recognise that there are two main disadvantages of this approach. First, coupling learning disability with a mental health review may create confusion about the nature of mental ill health and learning disability, which are two very distinct conditions. In particular learning disability is usually present from birth, it is a life-long condition that cannot be cured and people with a learning disability require educational and social supports as well as health and social services. We would recommend that in future such an approach to addressing needs should be avoided.

1.9 Second, concern has been expressed about the fact that other committees are addressing some of the specialised areas of policy and service development that will affect people with a learning disability. This includes child and adolescent mental health, adult mental health services, services for offenders and the mental health needs of older people. The Review has sought to address this in a number of ways:

- the Steering Committee has met monthly throughout this process to provide an opportunity for an exchange between committees on developments and to formulate an overarching vision and strategic direction
- the Steering Committee gave a clear direction from the outset that all Expert Working Committees must address fully the needs of people with a learning disability as they relate to their particular area of focus
- members of the Learning Disability Working Committee have been members of the other committees where possible to ensure that overlapping issues are addressed
- the conveners of each of the separate Expert Working Committees have met regularly to identify and agree mechanisms for addressing concerns as to the interface issues

- members of the Expert Working Committees have been invited to participate in seminars and events across the Review to enable sharing of ideas and developments

- draft copies of the Equal Lives Review were shared with conveners of the other committees at various stages to facilitate a read across from this report to those that are being produced by the other committees.

1.10 We recognise that concern persists about separate areas of policy being addressed in different reports. In response to these concerns we have highlighted at relevant sections of this report the areas that we expect will be addressed in other reports. In addition the Learning Disability Working Committee will continue to meet throughout the life of the Review to consider emerging reports and offer guidance where necessary on the links between those reports and the Equal Lives Review.

How Do We See the Way Ahead?

1.11 People with a learning disability in Northern Ireland do not enjoy equality of opportunity and are often excluded from the opportunities that other citizens enjoy. Their families frequently suffer high levels of social disadvantage and their caring responsibilities can place them under almost unbearable levels of stress. There is evidence of progress having been made, but in order to fully tackle these difficulties there is a need for major co-ordinated developments in support and services and a continuing change in attitudes over at least the next 15 years.

1.12 We believe this will be best achieved through the adoption of a shared value base, a focus on shared core objectives and rigorous efforts across Government departments and agencies in the community to implement the change agenda that is detailed in the Equal Lives Review.

Equal Lives Values

1.13 The Equal Lives Review is based on 5 core values with which all policy and service developments must be underpinned. These values offer guidance for future developments and should be enacted for all people with a learning disability irrespective of age, gender, severity of disability or complexity of needs.

Citizenship

People with a learning disability are individuals first and foremost and each has a right to be treated as an equal citizen.

Civil and human rights must be promoted and enforced. Government policy emphasises the importance of all citizens playing a role in civic society. People with a learning disability must be supported to be fully engaged in this agenda and their ability to exercise their rights and responsibilities needs to be strengthened. Citizenship recognises the unique contribution of each individual to their family and wider society and that the diverse strengths, needs and aspirations of people with a learning disability must be respected.

Social Inclusion

People with a learning disability are valued citizens and must be enabled to use mainstream services and be fully included in the life of the community.

Inclusion recognises both people's need for individual support and the necessity to remove barriers to inclusion that create disadvantage and discrimination. Inclusion is only possible on the basis of equality of opportunity to access and to participate in education, employment, leisure and other aspects of community life. Inclusion is more likely to be achieved if people's connections are maintained at a local level through involvement in local schools, housing, employment, etc.

Empowerment **People with a learning disability must be enabled to actively participate in decisions affecting their lives.**

Historically people with a learning disability have been excluded from decision-making processes and efforts must now be directed to affording opportunities to help them to learn how to participate effectively. They must be supported to have control, to have their voices heard, to make decisions about how they lead their lives and about the nature of support that they receive. Families and other carers need to be supported to enable people with a learning disability to take managed risks and lead more independent lives. It is recognised that some individuals with severe learning disability have particular difficulties with decision-making. For these individuals society needs to have robust arrangements in place to allow for substitute decision-making where required. The development of Mental Capacity legislation in Northern Ireland is ongoing through the Office of Law Reform and the Legal Issues Committee. We hope that this ensures transparent systems, based on promoting the human and civil rights of the individuals concerned.

Working Together **Conditions must be created where people with a learning disability, families and organisations work well together in order to meet the needs and aspirations of people with a learning disability.**

People with a learning disability must be central to planning and decision-making processes. The role of family carers as partners in these processes should be recognised and valued. A wide range of Government departments and agencies in the community, voluntary, statutory and private sectors will need to work together to meet their responsibilities to people with a learning disability. Making change happen requires those with a responsibility for education, housing, health, employment, leisure and social services to be fully committed and involved.

Individual Support **People with a learning disability will be supported in ways that take account of their individual needs and help them to be as independent as possible.**

Service systems that are based on group approaches need to be remodelled to more fully recognise people's individual strengths and needs. In particular people with a learning disability who have additional complex needs and their families may require highly individualised supports. Individual support will take a wide range of forms including staff, expertise, information and practical assistance. Individual support will also need to take account of the vulnerability of some people with a learning disability. Person centred planning will need to take account of this and ensure that appropriate risk assessments are completed as required. Where abuse or potential for abuse is identified, agency policies and procedures on the protection of vulnerable adults should be followed in the case of adults. Where the concern relates to children and young people the relevant sections of the Children (Northern Ireland) Order 1995 and associated multi agency child protection protocols should be followed. This approach will assist in managing the inevitable tension between the aspiration to accord full rights of citizenship to people with a learning disability and additional vulnerability that may be present as a consequence of the disability.

1.14 These values are a challenge to policy and practice, but are in keeping with recent legislative changes. The implications of these changes have not yet been fully realised in services, which traditionally have been based more on separation and dependency.

Equal Lives Objectives

1.15 We propose that future policy for improving the lives of people with a learning disability is directed toward attaining 12 core objectives over the next 15 years.

Objective 1	To ensure that families are supported to enjoy seeing their children develop in an environment that recognises and values their uniqueness as well as their contributions to society.
Objective 2	To ensure that children and young people with a learning disability get the best possible start in life and access opportunities that are available to others of their age.
Objective 3	To ensure that the move into adulthood for young people with a learning disability supports their access to equal opportunities for continuing education, employment and training and that they and their families receive continuity of support during the transition period.
Objective 4	To enable people with a learning disability to lead full and meaningful lives in their neighbourhoods, have access to a wide range of social, work and leisure opportunities and form and maintain friendships and relationships.
Objective 5	To ensure that all men and women with a learning disability have their home, in the community, the choice of whom they live with and that, where they live with their family, their carers receive the support they need.
Objective 6	To ensure that an extended range of housing options is developed for men and women with a learning disability.
Objective 7	To secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability.
Objective 8	To ensure that men and women with a learning disability are supported to age well in their neighbourhoods.
Objective 9	To enable people with a learning disability to have as much control as possible over their lives through developing person centred approaches in all services and ensuring wider access to advocacy and Direct Payments.
Objective 10	To ensure that health and social care staff are confident and competent in working with people with a learning disability.
Objective 11	To ensure that staff in other settings develop their understanding and awareness of learning disability issues and the implications for their services.
Objective 12	To promote improved joint working across sectors and settings in order to ensure that the quality of life of people with a learning disability is improved and that the Equal Lives values and objectives are achieved.

Making Change Happen

1.16 Twenty-first century services will need to attune to a changed perception of what it means to have a learning disability. Many people with this disability are capable of doing more themselves. Their needs and aspirations cannot be met solely by health and social services - they need support from education, housing, leisure, employment agencies and others.

1.17 We recognise that achieving these objectives will require a major programme of work that will include:

- changes to how funding is allocated
- securing additional resources to achieve key outcomes
- closer interdepartmental and interagency working
- significant attention to developing and reconfiguring the workforce
- setting up robust arrangements for ensuring the implementation of recommendations
- commitment and effective leadership from key decision makers, planners and managers.

1.18 We will set out in the chapters that follow a series of concrete recommendations that should be implemented to support the achievement of the Equal Lives objectives. These recommendations fit together like a jigsaw and provide a coherent framework for guiding the delivery of the change programme.

MESSAGES FROM PEOPLE WITH A LEARNING DISABILITY AND THEIR FAMILIES[5]

Chapter 2

See Me, Hear Me

> *We hope the Review will make sure that there are more advocacy groups and more chances for people to speak out and be listened to. We do not think this happens enough and that is why things go wrong.* (1)

2.1 Throughout the Equal Lives Review we have listened carefully to the views of men, women and young people with a learning disability. Often we were told that they are not listened to or given a full chance to have their views heard by those who are making decisions about them. We heard a very strong message that change is needed to the way that decisions are taken and the approach taken to respond to people's needs, wishes and aspirations.

Chances and Choices

> *We want the same chances as everyone else. Why is this such a problem?*
> Equal Lives Group Member

2.2 Many people told us about the different activities in which they are involved, but a lot of difficulties were also highlighted when people with a learning disability tried to make use of the same opportunities as others. Problems described included:

- difficulties for children in using the play opportunities that their peers enjoy
- serious problems in getting out and about because of a lack of suitable transport locally
- many men and women described how lonely they feel especially at weekends and the evenings when they have nowhere to go
- bullying was a big problem for many of the people we talked to. Some told us how unsafe they feel in their own homes and others described how they had been subjected to regular verbal abuse because of their learning disability.

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[5] Fuller details of these messages are contained in the reports of 3 of the consultations carried out as part of the Equal Lives Review. These reports can all be obtained from the Review website www.rmhldni.gov.uk.

- some of the men and women we met were keen to work or do further training but a lot of barriers were put in their way, including lack of opportunities, the perceptions of employers that they would not be able to do the jobs and the negative impact on their social security and other benefits if they took up employment.

> *I am ready to work but doors are always closed in my face because I have epilepsy and a learning disability. People don't want to know. Employers can't be bothered to have people with a learning disability.* (1)

2.3 Many people who attended the public meetings described how important it was to them to have friends who were not family members or staff. Lack of information about personal relationships and restrictions placed on such relationships were highlighted at each meeting.

2.4 For those who had been successful in accessing a range of leisure or work opportunities the benefits were huge.

> *They gave my son a life - he goes to the local youth club and joins in a lot of clubs just like any teenager.* Mother

Getting the Right Support

2.5 The importance of staff attitudes and skills was a recurring theme in all the meetings. When staff displayed knowledge about disability and sensitivity in their approach it had a very positive effect on the lives of both people with a learning disability and family carers.

> *My life has been totally changed lately. I got a new social worker a few months ago and suddenly I am getting a lot more help in the house. I got my first break ever a couple of weeks ago.* Mother

2.6 Families were very appreciative of many of the services they received. Feedback from parents whose son or daughter had profound disabilities or complex needs stressed the value of the support they received.

> *Trustworthy, familiar staff make my daughter feel confident.* **Parent (3)**
>
> *Work with the professionals at the day centre has definitely increased his life expectancy and improved his quality of life.* **Parent (3)**

2.7 Although there were some conflicting views among carers as to the type of services they wanted, they frequently described their efforts to get the right support as a battle. We were told that parents were often worn out and very fearful about the future for their sons or daughters. The concrete steps that would make a difference to family carers included:

- easier access to information about the help available to them and how to access it
- flexible breaks from their caring role and emergency support especially outside of normal office hours in the event of a family crisis
- more support in the home
- better training for staff and staff approaches that are based on respecting the expertise of the family carer and their central position in the life of their son or daughter
- improved access to practical changes to the home environment and provision of practical aids
- immediate implementation of the right to a Carer's Assessment and more tangible responses to the needs identified in those assessments
- better access to Direct Payments that meet both their needs and the needs of their relative in order to give them greater control in the nature of support provided
- planning processes that embrace the expertise of family carers and most importantly that lead to action being taken in response.

> *The parents are getting older and tireder, the children are getting older and lonelier, the pile of public sector strategies, plans, reviews and academic studies is getting higher and higher, meanwhile plus ça change plus c'est la meme chose. There's an industry of officials and professionals out there, supposedly supporting our kids but fellow stressed-out parents and the man who invented Playstations have probably done more for my child than the lot of them put together. That makes me mad, and sad.* (4)

2.8 The Equal Lives Group report clarifies what they believe is important in relation to support from staff. They want staff who:

- listen well
- know what they are supposed to do
- understand what to do in an emergency
- know a lot about learning disability.

They also stressed the importance of staff not wrapping them up in cotton wool and listening and acting on what they (the man or woman with a learning disability) felt was important.

Challenges of Complexity

2.9 Family members who care for a relative with complex needs had some very particular concerns. The complex needs related to those with an Autistic Spectrum Disorder (ASD) and learning disability, those with severe learning and/or physical disability, those with complex health needs and those with challenging behaviours. For many of these parents real concerns were expressed that the move towards social inclusion will lead to an even greater marginalisation of their family members. They were anxious that the social inclusion and equality agendas might not be open to addressing their concerns or meeting the needs and aspirations of their family members. It was noted that full involvement in community life is limited by the few facilities that are accessible and the negative attitudes of members of the public.

People stare all the time. **Parent (3)**

Public and some professional attitudes need to change. **Parent (3)**

2.10 Parents involved in the Challenges of Complexity (3) consultation made a number of suggestions:

- appropriate financial assistance to meet their accommodation needs
- improvements to day care to enable more sensory based activities and a wider range of activities
- communication training for all staff
- financial assistance to enable families to purchase a suitable vehicle
- changes in attitudes from all people to ensure all those with a learning disability, including those with very complex needs, can enjoy a full and meaningful life in their community.

2.11 The powerful messages we received from people with a learning disability and family carers have made an immense contribution to all our work on producing this report. This process of consultation and participation should be echoed throughout the work that will be required to implement the Equal Lives Review recommendations.

SETTING THE SCENE

Chapter 3

Modern Thinking About Disability

> *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.* (5) **United Nations (UN)**

3.1 In order to provide a context for understanding the issues which impact upon the lives of people with a learning disability this chapter will address a number of broad themes viz:

- rights and the law
- policy changes
- defining and assessing learning disability
- prevalence of learning disability
- the impact of the troubles
- service provision and funding
- inequalities and human rights.

Rights and the Law

3.2 The quotation from the UN typifies the radical shift that has occurred over recent years in how society perceives people with a disability. This shift has been demonstrated by a growing recognition in legislation and social policy that people with a disability are people first and foremost. The previous focus on what people cannot do is being replaced by an emphasis on how the impact of their disability might be reduced through appropriate support and the removal of barriers to their full participation in society.

3.3 Developments in Northern Ireland legislation have reflected these trends. The Northern Ireland Act (1998) states that *a public authority shall, in carrying out its functions in Northern Ireland, have due regard to the need to promote equality of opportunity between persons with a disability and persons without.*

3.4 Further legal entitlements of people with a learning disability and carers have been set out in legislation, which is summarised in Annex G. Recent legislation largely serves two main purposes.

- First, it ensures that people with a disability 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 a disability with the additional services and supports they require to assist them to achieve a better quality of life and social inclusion.

The Legal Issues Working Committee

3.5 The Learning Disability Working Committee is aware of the current detailed work of the Legal Issues Working Committee, much of which impinges on the lives of many people with a learning disability. Issues such as guardianship, capacity and incapacity, compulsory admission for assessment and treatment, the Mental Health Review Tribunal, advocacy, legal representation, are all matters which clearly connect with this report. Issues around inheritance, eligibility to vote, to marry and to engage in sexual activities will also need to be considered, along with finding effective ways of helping people with a learning disability to exercise their rights. It is our view that the future legislation will need to address these issues fully. This may require 2 separate pieces of legislation - one of which would address issues of mental capacity and decision-making and the second of which would address the legal issues for people with severe mental illness, irrespective of whether or not they have a learning disability. Learning disability interests are represented on the Legal Issues Working Committee and continue to be regularly articulated there.

Policy Changes

3.6 Changes in societal perceptions of disability are also reflected in the policy aspirations that underpin much of current service planning and delivery. These changes are clearly seen in the recent reviews of learning disability services undertaken in these islands over the past 15 years.

- The 1990 review of services in the Republic of Ireland was based on a philosophy that every one with a learning disability has the right to *as fulfilling and normal a life as possible.* (6)

- The last review of policy for people with a learning disability in Northern Ireland that was conducted by the Department of Health and Social Services in 1995 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.* (7)

- The Scottish Review - The Same as You? (2000) (8) - and the English Review - Valuing People (2001) (9) - were underpinned by a commitment to social inclusion, enabling people with a learning disability to have more control over their lives and securing equality of opportunity in accessing services in local communities. In 2001 the National Assembly of Wales set out the principles underpinning their framework for services for people with a learning disability in Wales, which similarly reflected a concern to secure equality, citizenship and improved quality of life for people with a learning disability. (10)

3.7 Over recent years the 4 Health and Social Services Boards in Northern Ireland have issued policy statements to guide their commissioning of services, each of which has echoed similar themes namely:

- inclusion within society as a right and the use of mainstream community services

- support to individuals that will reduce the impact of the disability on their lives

- focus on individual needs and aspirations and hence the provision of choices

- empowerment of people with a learning disability to make decisions
- partnerships are required to make these a reality. (11, 12, 13, 14)

3.8 These changes are also echoed in policy changes in relation to education, social security, children and family issues. All have been underpinned by aspirations to tackle inequality and open access to the opportunities that are available to other citizens in Northern Ireland.

3.9 It should be noted, however, that much of the evidence presented to the Learning Disability Working Committee indicates that these aspirational statements have not fully been translated into practice. In particular the Review of Policy and Services for People With a Learning Disability (1995) (7) pointed the way towards many of the changes that we are again highlighting in this report. The failure to fully implement the recommendations of that review appears to stem from a combination of the following factors:

- insufficient resources to build up the community infrastructure including community based alternatives to hospitals required to deliver on the strategic intent
- the lack of robust implementation mechanisms to hold all Government departments and agencies to account for their actions in implementing the recommendations
- the continued perception that the needs of people with a learning disability can be met solely by health and social services
- an underdeveloped culture of involving people with a learning disability and family carers in determining the services available to them.

3.10 The challenge for the future will be to build on the direction of travel that has been established in these legislative and policy developments and to learn from lessons of previous reviews to ensure that these aspirations become a reality within the next 15 years.

Defining and Assessing Learning Disability

Terminology

3.11 We considered the terminology that should be used to describe this condition, which included consultation with the Equal Lives Group to hear their views on the most acceptable approach. We recognise that the term *learning disability* has potential for confusion with the broader and educationally focused term *learning difficulty*. We also recognise that there is no universally acceptable term that defines people who have such diverse characteristics. Of greater significance will be the degree to which in the future those with a responsibility to reduce the negative impact of the disability address people's unique individual talents, needs and aspirations. We have decided to accept at this stage the advice of the majority of Equal Lives Group members who expressed a preference, if a term must be used, for *learning disability*. This will no doubt be the subject of ongoing debate as society continues to respond to the aspirations of those most affected by the implications of the term.

3.12 Learning disability is not easy to define. However, we recognise that in order to ensure that people with a learning disability qualify for the individual supports, protection and services they require, some form of working definition is required. Annex H summarises the definitions used nationally and internationally. Many of these focus solely on an individual's impairments and social functioning. Having examined a range of definitions we have adopted the definition used in Valuing People (9) and recommend the adoption of this form of words in future policy developments i.e.

3.13 ***Learning disability includes the presence of a significantly reduced ability to understand new or complex information or 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.***

3.14 In keeping with the Equal Lives model it is essential that account must also be taken of the person's social circumstances and the supports they require when applying these definitions.

Perceptions of Disability

3.15 Historically, definitions of disability, professional practice, and service delivery to people with a learning disability have been based upon a Traditional (Medical) Model of disability which suggests that it is primarily the individual's impairments that render them incapable of participating fully within society, and does not give adequate attention to the barriers imposed by society that exclude disabled people from participation and inclusion. During the past two decades however, the Traditional (Medical) Model of disability has been challenged and criticised on a number of fronts.

3.16 This has resulted in the development of what has become known as the Social Model of disability, which places a greater focus, or emphasis, on wider aspects of people's lives, including access to education, employment, health care, transport and housing, and the disabling nature of the barriers people face, in trying to access normal living.

3.17 However, we recognise that people with a learning disability are not a homogenous group, and that the needs of individuals can vary considerably. Therefore, it is our view that all services, across all sectors, should aspire towards a holistic, or bio-psycho-social model, encapsulated by inclusive and person centred approaches. This model allows for the holistic view of an individual's needs, implied by the core values of the Equal Lives Review.

3.18 This model includes the following:

- focus on the person and not the disability
- focus and emphasis on environmental and societal barriers that exclude people with a learning disability from society
- acknowledgment of the need for informed medical diagnosis and health care support
- can be applied across the range of learning disability
- use of a common and acceptable language to all
- forging professional and agency togetherness rather than divisiveness
- challenging segregated service provision and paternalistic practice.

3.19 Within this model there are four basic dimensions in describing the disabilities experienced by the person with a learning disability. These are depicted in Figure 1.

Figure 1

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.
4. **The supports** - (physical and human) available to the person and those that are lacking but needed.

3.20 Assessment on all 4 dimensions gives a more complete picture of the person, their life-style and needs. Equally 4 different terms (or more) should be used to locate the person within subgroups such as: *a 20 year old man with Down's 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

Why Assess?

3.21 A person needs to be assessed to establish if they have a learning disability for different reasons:

- to determine if they are eligible for services specially provided for people with a learning disability
- to find out if they qualify for legal protection accorded to people with a learning disability
- to make an assessment of the particular help or support they require because of their disability.

3.22 The assessment of a person's eligibility to services needs to be reconceptualised. The person's needs for services can be multi-dimensional as noted earlier. No longer is it reasonable to think in terms of one service; rather people may avail of many different services. Thus assessments of eligibility for services are rarely done on a once-off basis.

3.23 However, people with a learning disability do not need to be specially assessed to determine their eligibility for services that are available to the wider population as long as they meet the same criteria as their fellow citizens. We anticipate that this truism will have growing significance in future years.

3.24 In order to determine a person's needs for specific services, including provision for protection, that arise from their learning disability, the essential requirement is to specify the person's needs and vulnerabilities rather than their disability per se. In the past a low IQ alone was used to categorise persons deemed to have similar needs, but this is now being considered in tandem with an assessment of social functioning and a crude approach based solely on IQ should have no place in modern service provision.

3.25 The onus is on the service to precisely define the criteria that make a person eligible for the special service. Each defined service needs to produce and publicise the criteria for admission, especially for those services where demand exceeds supply, such as the provision of respite (short-term) breaks or attendance at day centres. The assessment of the person then becomes one of whether or not they meet the criteria for entitlement. This recognises the reality that everyone with a learning disability does not require every service. It also means that as people's needs change over time, they may become eligible for services; hence re-assessments of needs are required.

3.26 We view assessment of learning disability as an interactive process in which the person and their family carers are fully engaged with professional staff. This will necessitate services specifying more precisely their aims and criteria for admission while developing suitable and transparent means of assessing an individual's needs. There are encouraging signs that this is starting to happen in services, but it requires sustained attention in the coming years.

3.27 It is vital to ensure that a separate assessment of the needs of carers is conducted.

3.28 Until such times as present laws change, it is likely that thorough and precise assessments of intelligence and adaptive functioning will be required to determine if a person has either a significant or severe 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. We anticipate that the Review's Expert Working Committee on Legal Issues will make further recommendations on this issue.

How Many People with a Learning Disability are there in Northern Ireland?

Prevalence

3.29 We have experienced some difficulty in securing accurate information on the prevalence of learning disability owing to the way in which such information is gathered in Northern Ireland. However, a recent study based on information held by Health and Social Services Trusts estimated the numbers as shown in Table 1. (Data from the Republic of Ireland are provided as a comparison). (15)

Table 1: Prevalence Rates (per 1,000) (15)

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

3.30 These data suggest that many 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 *possibly having 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. 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.

3.31 There is a small, but growing population of people from minority ethnic communities in Northern Ireland. Data is not available from present data systems, although under Section 75 of the Northern Ireland Act (1998) it should be recorded as these individuals and their families may have particular needs that are not currently addressed.

3.32 Finally, these numbers represent people known to services at a particular point in time. It is possible that the actual numbers 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. This is especially so when those with milder forms of impairments, but allied with poor social circumstances, are included.

3.33 This would indicate that there is an unrecognised population of people with a learning disability of approximately 16,000 people who are currently not known to services.

Future Indications of Population

3.34 All the indications are that there will be increased numbers of people with a learning disability in the next 15 years. (17) This results from:

- increasing life expectancy - it is now thought that most adults with a learning disability in developed nations who live beyond thirty are likely to survive into old age and experience the normal ageing process
- people with more complex health needs are living into adulthood due to advances in medical care
- more mothers giving birth later
- increased survival rates of at risk infants due to improved healthcare
- the bulge in the numbers 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 learning disability in these populations could also result in increased numbers.

3.35 There are some trends that may result in decreasing numbers or degree of disability:

- better pre-natal care for all pregnant mothers including increasing availability of pre-natal screening for congenital and other abnormalities
- improved health care and early intervention for at risk infants leading to fewer becoming learning disabled
- the advent of gene therapy to correct or ameliorate congenital abnormalities.

3.36 Overall it is impossible to predict the impact of these opposing influences. 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 access 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 people. It might also be that numbers would continue to rise for a further 15 years, up to 2034 before deaths matched births.

3.37 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 service provision based solely on the number of service users.

3.38 These factors indicate the increased demands that will be placed on existing pressurised services and the need to significantly develop community services to meet increased need into the future.

3.39 There may be increasing numbers of people from ethnic minority communities if immigration increases in Northern Ireland as it has done in the Republic of Ireland and Great Britain.

Links with Social and Economic Deprivation

3.40 Internationally there is clear evidence for a link between higher prevalence rates of mild/moderate learning disability and poorer socio-economic status and unstable family backgrounds. (18) This link with a severe learning disability is less clear-cut, but more recent research internationally does suggest a link with socio-economic status. (19)

3.41 Research in Northern Ireland has identified a significant association between the indicators of socio-economic measures of deprivation and the prevalence of people with a learning disability recorded on service information systems irrespective of the severity of their disability. (20) This is based on a small area analysis of the characteristics of people living within each electoral ward (i.e. around 2,500 persons) as ascertained by the national census or other form of surveys using representative sampling.

3.42 In Northern Ireland the association is best captured by three indicators of deprivation, namely there tend to be more people with a learning disability in wards that 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.

3.43 However, families who have a member with a learning disability may be poorer for other reasons (refer to Chapter 4). Therefore, many people and families are disadvantaged not only because of the disability, but also because of social and economic deprivation.

The Impact of the Troubles

3.44 It is notable that in many of the studies done on the impact of the Troubles on individuals and families, 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 disability 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 men and women is non-denominational although the balance of attendees from one rather than another community can be determined by its geographical location. (21)

3.45 In common with other public institutions in Northern Ireland, special schools and services seem to have been silent about issues of division, conflict and sectarianism. (22) There appears to be limited engagement in any reconciliation initiatives.

3.46 The findings from studies undertaken with other populations in Northern Ireland are also likely to mirror the experiences of at least some people with a learning disability. These have been summarised in terms of impacts that are more frequently experienced and less visible, to those that are less frequently experienced but highly visible. (23) 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.

3.47 The clinical experience of professionals suggests that people with a learning disability were recruited by paramilitaries and that some were subsequently involved in serious offences.

3.48 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 legacies of the Troubles.

3.49 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.

3.50 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 2 main cultural traditions in Northern Ireland.

Service Provision

3.51 There is no accurate record of all services provided under the learning disability programme of care either by a Health and Social Services Trust or by a subcontractor in the private or voluntary sector. Nor are there accurate records of the number of people availing of them.

3.52 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 3 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
- in some areas there has been a shift in the provision of children's services from a learning disability programme of care to the generic family and child care programme and child health
- there has been a major growth in the provision of residential homes and nursing homes for people with a learning disability by a range of independent sector providers. Latterly increasing numbers of people have their own homes with staff providing support as required.
- there has been an increase in the range and quality of child care places but data available does not allow us to identify the extent to which children with a learning disability have benefited
- a wider range of day centres is available along with vocational training and employment services provided largely by the voluntary sector
- the provision of education for children with a learning disability has become the responsibility of Education and Library Boards and increasing numbers of these students go on to attend Further Education (FE) Colleges
- the health aspect of Early Intervention is now led by paediatric services with support from learning disability specialists
- a network of personnel from different disciplines and therapies are providing services to people with a learning disability living alone, at home and in community residential facilities
- a variety of different services have evolved to provide support to families and hardly any child or teenager now lives away from a family
- 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.

3.53 The result is a greater diversity of services with a wide range of personnel employed in them, which has produced a complex web of services spanning all sectors and a wide range of settings. However, this complex web of service provision has created its own particular difficulties including:

- family carers complain that they are not given information about all the services and help that is available (24)

- families may have to work with various different specialists who may give conflicting advice. The concept of a named or key worker for the family is not well established. (25)

- there is likely duplication within and across services in terms of record keeping, assessments and staff roles

- the full range of services is not available as often, new services have been developed in an area at the instigation of particular individuals or as a result of special project based funding. This produces inequalities within and across areas, a pattern that has been referred to as being a postcode lottery for support.

3.54 The need for joined-up working across different Government departments, statutory agencies and other service partners is very evident in the field of learning disability. It has received scant attention in Northern Ireland, although it is being actively promoted in Great Britain.

3.55 In recent years, increasing attention is being given to creating more person centred approaches in service delivery. 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. However, recent research has indicated that PCP on its own may be ineffective unless the cultures of organisations change radically to create a shift in the power relationships between staff and the people they are working with and changes are made in funding arrangements and staff training and supervision. (26, 27)

3.56 In subsequent chapters we will address these and other issues through a series of recommendations.

Funding

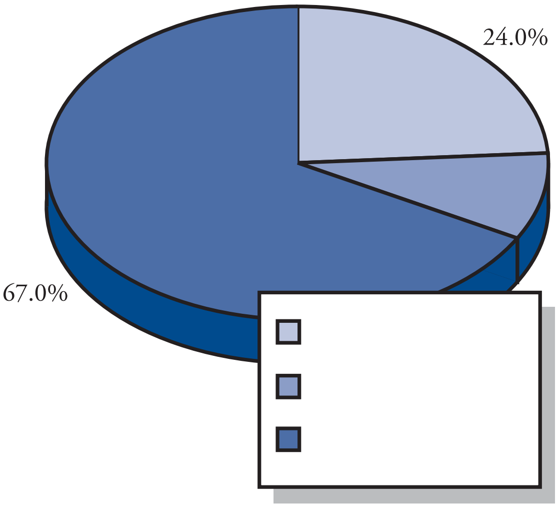
Health and Social Services Funding

3.57 The learning disability programme of care currently accounts for 7.6% of Health and Social Service Board expenditure (£136.4 million at 31 March 2003). This equates to approximately £80 per person of the total population. (28)

3.58 In the period 1997 to 2003 health and personal social services (HPSS) spending on the learning disability programme of care rose from £89.2 million to £136.4 million; an increase of 53%, although the later figure includes a substantial transfer of former social security payments to the HPSS. The share of the total HPSS spend also rose from 6.9% to 7.6%. (28) A detailed breakdown by key service area and by Health and Social Services Trust of the total learning disability expenditure for the latest available year (2002/2003) is given in Annex I.

3.59 The proportions of revenue monies spent in the HPSS learning disability programme of care as at 31st March 2003 are shown in Figure 2.

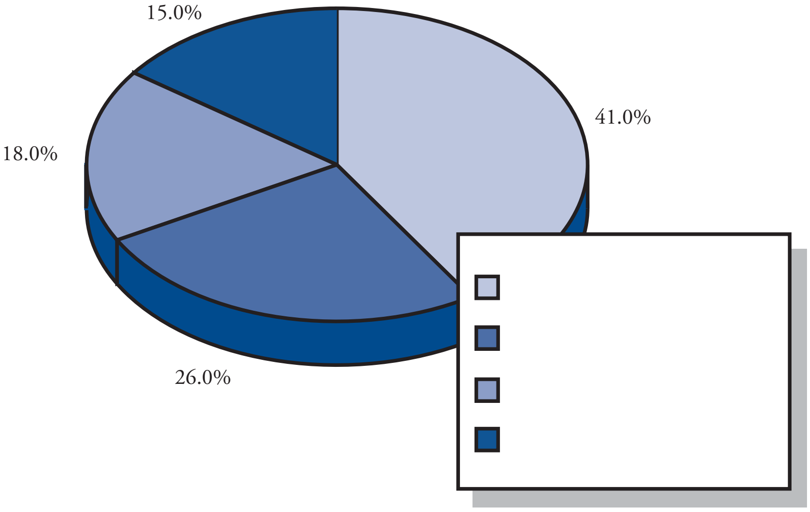
Figure 2: The proportions of monies spent in the Learning Disability Programme of Care - year-end 31 March 2003 (Total £136.4 million) (28)



3.60 There is a mismatch between the proportions of monies spent on hospital provision with the numbers of people in hospital settings (24% 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 as well as for the people who live in hospitals. Total hospital expenditure has shown an increase of 9% over the 7-year period from 1997 - 2003. The overwhelming majority of hospital expenditure recorded for the learning disability programme of care is for inpatients with just over 1.5% relating to outpatients and 2% to day patients. However, all the costs of specialist medical and psychiatric services and some other services are presently costed to hospitals although they also serve people living in community settings.

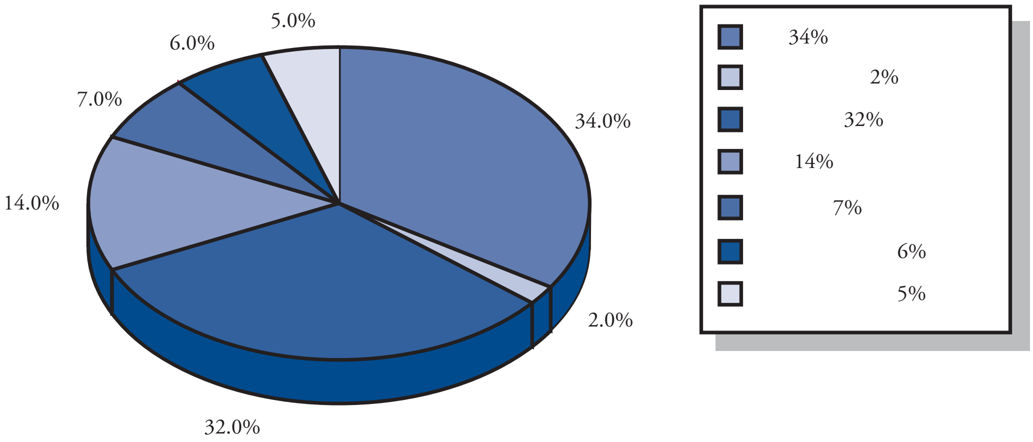
3.61 Community health expenditure has shown a 40% increase in the past 7 years, with the 2003 figure totalling £12.2 million (Figure 3). Expenditure on Allied Health Professionals includes speech and language therapy, physiotherapy, occupational therapy, etc as detailed at Annex D.

Figure 3: Learning Disability Community Health Expenditure 2002/2003 (Total £12.2 million) (28)



3.62 In personal social services (PSS) the largest items of expenditure recorded are residential homes/supported and other accommodation and day services as depicted in Figure 4. From 2002 onwards this received a major increase with the transfer of former social security payments to the HPSS. This was around £24 million but did not represent new monies, rather a reallocation of funds across Government departments.

Figure 4: Learning Disability PSS Expenditure 2002/2003 (Total £91.2 million) (28)



Funding From Other Sources

3.63 It has been difficult to obtain precise figures for the amount of monies spent by other Government departments on people with a learning disability. This will include:

- **Department of Education (DE):** on statutory assessments and statementing; the provision of learning support in mainstream schools and special schools
- **Department for Social Development (DSD):** 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 for Employment and Learning (DEL):** further education costs, vocational training, Disablement Advisory Service and career guidance
- **European monies** have provided funding towards various learning disability services, although it is anticipated that these will end in 2006 or soon after.

Variation in Costs

3.64 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.

3.65 Most research in Great Britain has focused on different forms of residential care and found that costs vary dramatically within all forms of residential services. There can be a 4-fold difference in costs of these services and similarly a 3-fold difference has been reported for day services. (29) The level of dependency of the residents accounts for a proportion of the variation. However, 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.

3.66 Newer community based services are generally more expensive than support provided in older style accommodation, although this largely results from compensating for the inadequacies of these services rather than inherent economies of scale in larger establishments.

3.67 A Northern Ireland study into the costs of providing residential services for people relocated from a long-stay hospital 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). (30)

3.68 Another study into the costs of supported living reported a wide variation in weekly costs, which were on average lower than figures cited for similar schemes in England, although some of these services employed waking night staff, which increases costs markedly. (31)

Inequalities and People with a Learning Disability

3.69 There is ample evidence to demonstrate that people with a learning disability do not have access to the same range of services and opportunities as other people in Northern Ireland.

3.70 The table, which follows, gives some examples of the inequalities that have been highlighted to the Equal Lives Review.

Table 2:	Inequalities Linked to Learning Disability
Children, Young People and their Families	Many children are unable to access mainstream play and leisure activities. (32) Access to preschool facilities for these children is curtailed.(33) Mothers are less likely to be in employment.(34) Mothers are more likely to report symptoms of ill-health such as depression. (35) The burden of caring is more likely to fall on the mother. (32, 36) 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. (37) Siblings of severely learning disabled children may also face inequalities with many having less contact with friends and increased levels of anxiety compared to other children. (38) Transition from school to adult services is a particular area of concern for parents. In the past commissioners and service providers have failed 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. (39)
Adult Life	People with a learning disability do not have the same opportunities in employment, further education, leisure, social life and personal relationships. Poverty contributes to some of these. Fewer people with a learning disability achieve accredited qualifications.
Health and Wellbeing	There are high levels of unmet health needs among people with a learning disability in Northern Ireland. (40, 41) Some may have a higher incidence of physical health problems. (41, 42) A person who displays challenging behaviours[6] 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. (43) Those with the most severe behavioural problems are also more likely to be excluded from day opportunities such as day care or school. (44) People who challenge services are frequently the last people to move out of institutional care (45) and the ones most likely to be admitted to hospitals for specialist assessment and treatment. (46, 47)

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

People who commit offences may not come before the courts but will have to live in more confined and highly supervised settings, often long-stay in hospitals. (48)

Growing Older

Many older people with a learning disability are at particular risk of neglect, poor access to health care and marginalization within society. (49, 50)

Some people with Down's Syndrome age prematurely and life longevity is reduced for many people with severe and profound disabilities. (49, 50)

Human Rights and Discriminatory Practices

3.71 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. (51,52) These rights include the right to life, the right to liberty and security and the right to respect for a private and family life. These rights should never be restricted solely on the basis of the presence of a learning disability.

3.72 Questions do need to be asked however with regard to the inequalities that may exist in Northern Ireland detailed in Table 2. For example are statutory services in breach of the Disability Discrimination Act and Human Rights Act if they:

- fail to provide adequate community support for a person with challenging behaviours?
- exclude a person from day facilities or school because they do not have a nurse to care for his or her complex health needs?
- maintain a person in hospital because they do not have a facility in the community for a client to resettle to?
- deny access to health screening and treatment for a person by virtue of inaccessibility or exclusionary practice?
- do not have in place services to adequately meet the needs of older people with a learning disability?
- fail to provide family support, for example, respite?

3.73 Future legal challenges may test the legality of failure to provide adequate services in relation to the issues identified above.

Addressing Human Rights Issues

3.74 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 to address human rights and equality issues. It is our belief that in order to effectively address these issues services should be guided in future by the 5 values on which the Equal Lives Review is based: social inclusion, citizenship, empowerment, working together and provision of individual support. In addition efforts must be harnessed to change the attitudes and mind sets that support such discrimination and inequality. Various writers have noted that legislative implementation needs to be combined with:

- education of service staff who may discriminate against people with a learning disability
- moving 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
- involving people with a learning disability in the design, delivery and management of services.

Possible Inequities in Service Provision

3.75 There are difficulties in comparing service provision between one area and another because of the limited information available, the lack of reliable research studies in this area and differences in the way services are provided. Despite this caution there do appear to be some marked differences in Northern Ireland service provision when compared with other countries e.g.:

- Northern Ireland has the highest proportion of people resident in long-stay hospitals:
  - 15 places per 1 million population in England and Wales (9)
  - 163 places per 1 million in Scotland (8)
  - 222 places per 1 million in Northern Ireland (15)
- There are many more places provided (or to be provided) in Northern Ireland hospitals for assessment and treatment admissions:
  - estimated 203 places presently available in Northern Ireland/ 11.9 per 100,000 population reducing to 146 (excluding forensic and children's places) (based on figures supplied by HSS Boards)
  - 3.98 per 100,000 population in Scotland (53)
- In Northern Ireland over one quarter of people with a learning disability surveyed 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. However, the proportion of nursing home places varied within Northern Ireland; the Northern Health and Social Services Board (NHSSB) having the highest proportion (46%) and the Western Health and Social Services Board (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 the Eastern Health and Social Services Board (EHSSB) having the highest proportion (31%) and the Southern Health and Social Services Board (SHSSB) and WHSSB the lowest (4%).

- None of the Health and Social Services Trusts in Northern Ireland achieve the minimum number of funded accommodation 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 Health and Social Services Trusts from 6.8 places per 10,000 to 13.8 places per 10,000.

- More people with a learning disability attend 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). (54) 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 be that people in Northern Ireland have less access to further education, supported employment and ordinary leisure opportunities in comparison to people in Britain.

- In Great Britain not only do more people with a learning disability attend FE colleges (5.7% compared to 4.1% in Northern Ireland in 1999), but more are enrolled on a full-time basis (45% compared to 11%). (55) More recent figures supplied to the Equal Lives Review by the Department for Employment and Learning indicate that in 2002/03, 5.3% of all enrolments in FE colleges were for people with any form of learning difficulty or disability but this ranges from 1% to 13% across the 16 colleges in Northern Ireland.

- Although there are no centrally collated statistics in Northern Ireland, there appear to be more opportunities for people with a learning disability to be in supported employment in Great Britain and the Republic of Ireland. (16, 54, 56)

Future Prospects

3.76 It is important to end this chapter by highlighting the many positive achievements that have occurred within services for people with a learning disability in Northern Ireland over the past decade which have included:

- an increase of 53% in health and social services spending on people with a learning disability since 1997

- 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 reduced use of hospital provision to meet this need

- the reduction by 300 in the numbers of people living in long-stay hospitals since 1994

- the increase in expertise and support services that have enabled people with a learning disability and challenging behaviours to live in the community

- 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 wider range of innovative day opportunities that has been developed
- the greater acceptance by society of the rights of people with a learning disability and their willingness to include them in community life.

3.77 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 proposals for change that follow. It will be essential that data be collected to monitor these changes across all public services. This is already a requirement under Section 75 of the Northern Ireland Act 1998.

CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES

Chapter 4

> *The challenge to the Review is to get beyond the rhetoric and the research to recommendations that will get us closer to the vision of a world in which children with a learning disability will have equal choices and equal value.* **Children and Young People's Task Group.** (57)

Objective 1 To ensure that families are supported to enjoy seeing their children develop in an environment that recognises and values their uniqueness as well as their contributions to society

4.1 Recent trends in Government policy and legislation have emphasised the rights of children and the need to ensure equality of opportunity for all children. We have taken full account of the proposed children and young people's strategy for Northern Ireland and its welcome emphasis on including all children. However, frequently the particular needs of children and young people with a learning disability have tended to appear as a footnote in the initiatives that have emerged, but these are overshadowed by the numbers and needs of other groups. Children and young people with a learning disability have not benefited as they should from initiatives to improve children's experiences, or from measures focused on learning disability issues. We are proposing that there is an urgent need to address this situation in the firm belief that investment in children and young people is the most effective means of changing the experiences of people with a learning disability and their families.

Issues and Concerns

4.2 Many children and young people in Northern Ireland suffer from poverty and social disadvantage; these factors are increased where a family member has a learning disability. In Northern Ireland:

- 27% of the population is aged under 18 (58) making Northern Ireland the most youthful region in Europe yet we spend 25% less proportionately than England on children's services (59)
- 6.3% of children under 16 years live on family farms with an increased risk of isolation for all children and presenting serious challenges to families and services when a child has mobility problems (58)
- 29% of households are defined as poor with a further 12.1% vulnerable to poverty owing to low income. Half of these households include at least one member with long-term illness or disability (60)

- bullying is a significant cause for concern and unhappiness for children and young people with a learning disability. (61)

4.3 The views of children and young people with a learning disability are not routinely sought. When this is done it emerges that they share similar hopes and fears with their non-disabled peers, but also have additional specific concerns including difficulty having friendships, experience of bullying, isolation and barriers to play and leisure opportunities. (59, 62, 63)

Family Support

4.4 All children have the potential to bring to families great joy and equivalent levels of stress. Families are important to all of us, more so to the person with a learning disability. Families of people with a learning disability provide care and support well beyond what is normally expected and over a longer period of time. Families of children with a learning disability will at times report experiencing increased family harmony and cohesion, and higher levels of empathy among family members. For many other families however there can be preponderance of more negative experiences that drain the parent's or other main carer's ability to function as both an individual and as a long-term carer. (64)

4.5 The risk of experiencing such negative emotions is increased significantly for families:

- where the child has additional complex needs e.g.
  - children with multiple physical and sensory disabilities
  - children with an Autistic Spectrum Disorder
  - children who display high levels of challenging behaviours or mental health problems
  - families with more than one child with a significant disability
  - children whose disability is not easily identified and who don't look disabled
  - families where a parent has a learning disability
- at times of transition or change for the family e.g.
  - at the time of diagnosis
  - starting school
  - leaving school
  - transition to adulthood
  - leaving the family home. (65)

4.6 Children with a learning disability can display a range of special needs which require family members to fulfil a diverse range of roles and functions: parent, educator, communication facilitator, behavioural specialist, emotional confidant, advocate. Few carers could innately possess such a range of skills and, as such, need support and opportunity to acquire such skills. (66)

4.7 Positive developments in the support provided to parents over recent years include:

- increase in the number of Allied Health Professionals

- development in some areas of community based provision that facilitates access by children with a learning disability to community social and leisure opportunities

- the wider range of short-break options available to families and the reduced use of hospital provision to meet this need.

4.8 However, practical and emotional support to families tends to be fragmented and patchy. Although examples of good practice were presented to the Equal Lives Review, there was no evidence that such practice is consistent across Northern Ireland. Recurrent concerns presented to the Equal Lives Review included:

- Respite is currently defined as *placements, which are usually planned in advance, where a child moves out of the family home for a short break.* Provision is variable in Northern Ireland and parents frequently complained about their inability to access this provision particularly in emergencies.

- Provision of childcare has improved overall since the Government launched its most recent childcare strategy for Northern Ireland, Children First. (67, 68)

- The need for additional support for children with an Autistic Spectrum Disorder and/or multiple disabilities was highlighted to the Equal Lives Review.

- In addition there is an emerging need for additional provision after school and for older children.

4.9 Family support is not just about more services of whatever type being delivered to families in the hope that the cumulative effect will be helpful. Evidence has emerged in recent years both from outcome based research and families' own views that there are key elements of a Family Support model, which are crucial to successfully helping families cope. (65, 69)

Growing Areas of Need

4.10 There will be a number of growing areas of need over the next 15 years, which include:

- children who are technology dependant, an increasing number of whom are surviving into adulthood

- children with a learning disability who also have an Autistic Spectrum Disorder. Autism is a complex developmental disability of lifelong duration. The majority of those with an Autistic Spectrum Disorder do not have a learning disability and 75-90% are within the average or above average range of intellectual ability. (70) There is increasing evidence of the real life challenges experienced by these individuals who are often caught between learning disability, mental health and child health programmes of care. For those children with both an Autistic Spectrum Disorder and learning disability there is a need for appropriately skilled diagnosis and assessment and individual supports that take account of their particular needs. A ten year strategy to address the educational needs of children with Autistic Spectrum Disorders was detailed in the Task Force on Autism report. (71) Implementation of its recommendations requires close cooperation between the wider education sector and health and social services agencies.

- children with multiple severe and profound disabilities who require 24-hour personal care and increasingly intensive nursing care

- the numbers of children from minority ethnic communities are increasing

- increasing number of parents with a learning disability who may require additional supports to enable them to meet their parenting responsibilities. A survey in one Health and Social Services Trust found that 11% of families known to the children's disability team had 2 or more children with disabilities and for 5% of families one or both parents had a learning disability themselves.
- the nature of the family is changing. There are more lone parents caring for children with special needs. (72, 8)

Looked After Children

4.11 Children and young people grow and develop best in their natural families. Where the family can no longer provide the care or where the risks associated outweigh the benefits, this is not the case. Data are 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 EHSSB found that 53 children with a learning disability were living in some form of residential accommodation (N=31) or with foster carers (N=22). (73) This represents 0.28 per 1,000-child population or 3.3% of children with a learning disability in the Board. 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. (16)
- However, the study in the EHSSB area found that an additional 16 places were required to meet the needs of those young people presently living with families and that a further 14 places are also needed for those inappropriately residing in hospital or adult residential accommodation. 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 in settings appropriate to their needs. Many of these young people have severely challenging behaviours and/or an Autistic Spectrum Disorder. They are difficult to foster because of their complex behavioural problems or health needs and they cannot be accommodated in mainstream children's homes. The lack of appropriate community provision results in some of these children being admitted to adult wards in learning disability hospitals and the lack of adequate provision makes it difficult to discharge them.
- Mainstream children's homes have difficulties supporting children with a learning disability, but where for an individual child it is appropriate that they do, staff require additional training and support to carry out this role.
- The lack of residential and foster placements is a recognised problem for all children. In a Social Services Inspectorate report in 2003, 95% of respondents reported a shortage. Social workers surveyed said that 17% of children with a disability always/nearly always did not have their needs met. Multiple care placements were identified as a serious challenge. (74)

Action Required

4.12 We propose that support to families with a child with a learning disability be remodelled to develop responses that are:

- more family directed
- continuously identify the needs and wishes of the family
- empower staff to support families in a more family directed, purposeful way
- able to direct resources flexibly.

4.13 In order to develop a more co-ordinated approach and to overcome many of the difficulties associated with families not knowing what support is available to them, a key worker should be appointed as soon as possible after diagnosis. This role has been recommended in other recent reports but as yet remains to be implemented in any consistent manner across Northern Ireland. It is imperative that a key worker be identified who will be linked with the family early and assume primary responsibility for co-ordinating service intervention and delivery. The key worker will be drawn from existing professionals such as social work, nursing or allied health professionals. The key worker will ensure that a Family Support Plan is agreed in partnership with the family that clarifies the support the child and family requires and how it will be delivered. The family and key worker should review the Family Support Plan annually. **(Recommendation 1)**

4.14 Respite services need to be developed in a manner that moves away from an over reliance on inflexible residential provision to the provision of a menu of short break services that include home based support, community based activity, family placements and residential options. The range of responses must take account of the intensive or specialist support needs of some children.

4.15 Children's Services Plans must detail how they will address the growing needs identified above with particular reference to deficiencies in short break provision, childcare and support in the home of families of children with Autistic Spectrum Disorders, complex health needs and/or multiple disabilities. **(Recommendation 2)**

4.16 It is vital that families have easily identifiable and accessible points of contact at different stages of their child's life. In the coming years, multi-agency centres should be developed to act as a focus for both generic and some specific services. These could be established from existing service sites, such as family centres, large primary care practices, community centres, nurseries or schools, but their existing remit would be widened through the addition of other information, support personnel and services. The goal would be to create a hub for supporting families so that help can be wrapped around the child and the family. This one-stop shop would also act as a common point of contact for children, their families and the staff who support them and would help to build clear referral pathways to further help and support and provide better co-ordinated responses. Children's Services Planning should be charged with developing this proposal in that such centres would be designed for all children in need and not just those with a learning disability. The evaluations of Children's Centres in England and the Wraparound Pilot in Northern Ireland provide models of service and evidence of the factors that contribute to success. (75, 76) **(Recommendation 3)**

4.17 As noted above we recommend that family support including planned breaks and emergency care in and away from home be prioritised in order to minimise family breakdown. To meet the needs for additional placements for looked after children specialist fostering and adoption should be further developed to ensure targeted recruitment of and enhanced support for foster and adoptive parents. Places for young people with a learning disability and complex needs aged 14 - 18 years who cannot be placed in a family situation should be provided in ordinary domestic settings and with regard to the principles of individual support, continuity and security of tenures of the supported living model. **(Recommendation 4)**

4.18 In order to address the complex and particular needs of children and young people with challenging behaviours and/or severe mental health problems community based assessment and treatment services need to be further developed. **(Recommendation 5)** The Child and Adolescent Mental Health Working Committee will make further recommendations in relation to children and young people with mental health problems. The interface between these services will be a key implementation issue.

4.19 Objective 1 Recommendations

Recommendation 1	Each Trust should have established arrangements for the development of Family Support Plans, which must be delivered through a co-ordinated strategy that monitors outcomes and identifies unmet needs.
Recommendation 2	Over the next 5 years providers should be resourced to extend the volume and range of emotional and practical help to support families. Their proposals should be considered within the context of Children's Services Planning and be aimed at assisting the maximum number of families. An ear-marked fund of up to £2 million recurrent each year for 5 years should be made available to fund proposals that best meet the Equal Lives values and objectives. The outcomes from this Family Support Fund should be carefully evaluated and used to inform future commissioning decisions in support of family carers.
Recommendation 3	Health and Social Services Trusts in partnership with Education and Library Boards and the community and voluntary sector should establish multi-agency centres, which provide a clear pathway to help for parents of children with a learning disability.
Recommendation 4	By March 2006 each Health and Social Services Board should identify the need for permanent placements for children and young people with a learning disability and produce strategies to address them. While the focus should be on innovative means of developing and supporting specialist fostering, it may be necessary to commission intensive care provision for small numbers of children who can not be placed in family settings.
Recommendation 5	Community based assessment and treatment services should be developed for children and young people with severe challenging behaviours and/or mental health problems. The service should encompass a small short-stay residential provision and community behavioural support services that provide outreach to families, schools and community based agencies.

Objective 2 To ensure that children and young people with a learning disability get the best possible start in life and access opportunities that are available to others of their age.

4.20 Energies need to focus increasingly on directly meeting the individual needs of babies and young children in a co-ordinated manner. As they grow older barriers to their inclusion in play and leisure opportunities enjoyed by their peers must be removed.

Issues and Concerns

Early Intervention

4.21 The value of early intervention with children with a learning disability has been well recognised, but the problems and challenges that exist are evident: (64, 68, 70, 77, 78)

- professional efforts are often not co-ordinated
- parents complain of having to manage multiple appointments and receiving at times conflicting advice
- long delays are reported for appointments to specialists
- key services are understaffed (79, 80)
- not all children with a learning disability receive a clear diagnosis despite the presence of complex needs. This can result in children losing out as service responses are often linked to diagnosis.
- families report that lengthy multiple assessments can often result in little direct therapeutic or education intervention
- parents also report great difficulties in accessing the information they need to fulfil their parenting responsibilities including information on support, benefits and their child's condition.

Play

4.22 To play is one of the fundamental rights as stated in Article 31 of the UN Convention on the Rights of the Child. There is an urgent need to address the invisibility of disabled children in almost all the forms of play provision. For many children with a learning disability current provision is still too often inaccessible, unwelcoming and fails to meet their needs. Attitudinal or logistical barriers often currently exclude children with severe and profound disabilities, an Autistic Spectrum Disorder, severe communication difficulties or challenging behaviours, from almost all forms of publicly funded play. (81)

4.23 Play provision using the child's home as the base can build the confidence of both child and parent to use the other forms of play provision. Toy Libraries, Sure Start and outreach from Child Development Clinics have the potential to enhance the quality of children's play at home. Home visiting services have demonstrated their value in promoting the importance of play to parents and developing parents' play skills in the early years. (82)

4.24 Policy and provision to promote play needs to take sufficient account of the very different role and form of play in the lives of children at different stages of their childhood. Many children with profound and multiple disabilities or complex health needs spend significant periods of time in hospital. Disabled children also spend time away from home using short break services and again the emphasis is all too often on care rather than play. All of these services used by children with a learning disability would benefit from more focus on play. (64)

Young People

4.25 Young people with a learning disability express the same aspirations as other young people to independence, work, learning, friends, marriage and a home.

- The experiences of young people with a learning disability are characterised by isolation and lack of social opportunities, creating over-reliance on families.

- Youth services identify the inclusion needs of young people with a learning disability as an equality issue but lack the resources to take forward the recommendations of pilot studies. (83)

- The vulnerability of these young people to mental and physical health problems, sexual exploitation and crime as both perpetrators and victims is well documented but little preventative or reparative work is done. (61)

- In learning disability services youth can get forgotten between children's and adult services. In mainstream services young people with a learning disability have difficulty getting heard. Young people with complex needs are further excluded. There is a need for agencies to come together to address these issues across sectors and other administrative divides.

- Young people need to be supported to engage with the authorities to ensure their views are heard. The Interdepartmental Group that has been established by the Department of Education and Department of Health, Social Services and Public Safety to develop the range of support for children with special needs is an opportunity to ensure the broader agenda of young people's issues are addressed.

Action Required

4.26 In order to address the pressing need for information Health and Social Services Trusts should engage with partner agencies to develop accessible and timely information. This should be sensitively communicated to families at the point of diagnosis and at other major transition points. (78) There may be merit in exploring the feasibility of developing this at a regional level. **(Recommendation 6)**

4.27 In order to ensure that the needs of individual children are addressed in a more co-ordinated and effective manner the Family Support Plan should be complemented by the development, following diagnostic and assessment processes, of an agreed multi-agency Early Intervention Plan that is child centred. **(Recommendation 7)**

4.28 To address the current duplication and confusion about professional roles and boundaries and to support the development of key workers and effective Early Intervention Plans the Department of Health, Social Services and Public Safety and Department of Education should produce a comprehensive Early Intervention strategy that will:

- clarify pre-school years areas of responsibility between health and education
- consider how early intervention can be developed across all sectors including the training and research required in this area and also links within schooling
- review current provision models and resourcing
- extend and integrate the models of service that are currently being established for children with an Autistic Spectrum Disorder and which apply equally to children with other developmental disabilities. (71, 84, 85) **(Recommendation 8)**

4.29 The Department of Education and Department of Health, Social Services and Public Safety have a key role in ensuring equality of opportunity and addressing the needs of children with a learning disability. In order to achieve the objectives of the Equal Lives Review there will be a need for closer working and shared planning and funding where necessary. **(Recommendation 9)**

4.30 Children and younger people with a learning disability should have equal access to and benefit from play and leisure opportunities including sports and the arts. The Equal Lives Review has been encouraged to learn of initiatives in each of these areas that have included children and young people with a learning disability in community based play groups, after school clubs and youth services. However, there remains a lack of locally based accessible provision particularly for children and young people with profound and multiple disabilities. This needs to be addressed by ensuring that key agencies implement plans to reach children and young people with a learning disability. Public bodies should, therefore, require that the sports, leisure and recreational services for which they have responsibility evidence that they have been inclusive by monitoring uptake of their schemes and use of their facilities. **(Recommendation 10)**

4.31 In addition the Youth Service should mainstream the lessons learned from the pilot projects on inclusion and provide the support to ensure that young people with a learning disability get involved in decision-making processes in youth and other civic activities. **(Recommendation 11)**

4.32 Greater attention needs to be paid to addressing the increased vulnerability of children and young people with a learning disability to abuse and exploitation. The school curriculum for these pupils should encompass personal safety and personal relationship issues. **(Recommendation 12)**

4.33 The appointment of a Commissioner for Children and Young People in 2003 was a welcome development and the proposed children and young people's strategy should harness the efforts of a wide range of Government departments and other agencies towards achieving equality of opportunity for all children in Northern Ireland. The Commissioner could play a key role in ensuring that all agencies meet their inclusion objectives for children and young people with a learning disability. **(Recommendation 13)**

4.34 Objective 2	**Recommendations**
Recommendation 6	Each HSS Trust should set in place mechanisms to ensure that information on services and how to access them, benefits and support groups and other sources of help is automatically supplied to families at diagnosis/birth of their child.
Recommendation 7	Each HSS Trust should establish arrangements for the development of an Early Intervention Plan, which includes details of a key worker, for each child with a learning disability at his/her birth/diagnosis.
Recommendation 8	By June 2007 the Departments of Education and Health, Social Services and Public Safety should develop a regional strategy for early intervention.
Recommendation 9	By January 2007 joint planning and bidding mechanisms should be developed by the Departments of Education and Health, Social Services and Public Safety for services for children and young people with a learning disability.
Recommendation 10	The Department of Culture, Arts and Leisure, Arts Council, Sports Council, Education and Library Boards, Youth Council and District Councils should produce clear statements outlining how they are targeting provision for play, sports, arts and leisure opportunities for children and young people with a learning disability.
Recommendation 11	The Youth Service should mainstream the lessons learned from the pilot projects on inclusion and provide the support to ensure that young people with a learning disability get involved in decision-making processes in youth and other civic activities.
Recommendation 12	The Department of Education and Education and Library Boards should review the effectiveness of the programmes of learning for children and young people with special educational needs in relation to issues of personal safety and personal relationships. This should be supported with awareness programmes for parents and for others involved with children and young people.
Recommendation 13	The Commissioner for Children and Young People should be requested to monitor the effectiveness of all authorities in meeting their inclusion objectives. To facilitate this, the relevant departments should produce an Annual Report on the implementation of action plans.

FULLER LIVES

Chapter 5

> *I want my son to have a chance at education, to have friends, to get a job that he enjoys. Isn't that what you want for your children? Why should we be any different?*
> **Mother**

5.1 Ensuring that men and women with a learning disability are able to actively participate in their communities and afforded opportunities to meet their aspirations for meaningful day-time activities, friendships, employment, education and leisure was a key area of concern to all those who contributed to the Equal Lives Review. This chapter explores some of the issues highlighted and outlines a strategy for improvement that will require the active commitment of a range of Government departments and more effective working together between agencies, men and women with a learning disability and family members.

5.2 There is a pressing need to reform outdated policies and practices that are based on a belief that these issues should be addressed within the context of health and social services provision. An alternative model is required that challenges the social exclusion of men and women with a learning disability from mainstream services and proactively ensures their access to the same range of education, employment, personal relationships and leisure opportunities, whilst ensuring that individual support is available where required. Linkages with the revised anti-poverty strategy and actions are essential if we are to overcome social disadvantage and exclusion.

Objective 3 To ensure that the move into adulthood for young people with a learning disability supports their access to equal opportunities for continuing education, employment and training and that they and their families receive continuity of support during the transition period.

Objective 4 To enable people with a learning disability to lead full and meaningful lives in their neighbourhoods, have access to a wide range of social, work and leisure opportunities and form and maintain friendships and relationships.

Issues and concerns

5.3 The key issues may be summarised as relating to:

- the transition to adulthood
- supporting men and women with a learning disability who have complex needs

- further education
- day services
- employment
- transport
- leisure
- personal relationships.

Transitions

5.4 Education and Library Boards have key duties in planning for a young person's transition into adult life and are required under the Education Order (NI) 1996 to :

- inform Health and Social Services Trusts up to a year in advance of a young person with a statement of Special Educational Needs leaving school
- prepare a Transition Plan to allow for the coherent transition of the young person to adult life in partnership with parents and other agencies.

5.5 However, despite evidence of excellent practice including innovative initiatives in partnership with the voluntary sector, the experiences of many young people leaving school have been unsatisfactory.

- Various studies have documented the various difficulties that parents and young people have encountered during the transition years. (39, 63)
- Much of the planning occurs in the last year at school, which is too late to ensure that a range of options are sampled or explored.
- Careers advice is available to young people with a learning disability through the Careers Advisory Service. Input to individual schools varies but is better where good relationships have developed between the Careers Officers and the teachers.
- There is a striking contrast between the expectations of parents and young people and the lack of options that are available to them after school. (63)
- There are examples of good practice throughout Northern Ireland where partnerships between the voluntary and community sector and schools have resulted in positive outcomes, but there is no consistent access to such initiatives across Northern Ireland.

Complex Needs

5.6 There are a growing number of men, women and young people with a learning disability who have complex needs and multiple disabilities.

- Parents report that access to the services of Allied Health Professionals reduces upon leaving the special school.
- A growing number of young people who challenge services, some with a history of school exclusion.

- A few will commit offences and therefore come into contact with the criminal justice system.
- There are increased numbers of school leavers with a learning disability and an Autistic Spectrum Disorder.
- There is increasing evidence of dementia and Alzheimer's Disease amongst older men and women with a learning disability.

Further Education

5.7 There is scope for development of opportunities for men and women with a learning disability within Further Education (FE) in Northern Ireland.

- Significant variation exists across colleges in the number of students with a learning disability enrolled as a proportion of the student body ranging from 1% - 13% in 2002. (86)
- Average level of enrolments appears to be lower in Northern Ireland, 4.1% in 1999, as compared with 5.7% in England. (55)
- The number of students enrolled on full-time courses is also lower, 32% in 2002 in Northern Ireland (ranging from 10% to 67% across the Colleges) as compared with 45% in England in 1999. (Department for Employment and Learning and 55)
- Concerns exist about the lack of progression from FE provision; students not able to gain accredited awards from their study; the lack of links with job training and work experience; students repeating the same course content in subsequent years.
- It is encouraging that studies in Northern Ireland have highlighted a range of initiatives that are affording positive opportunities for young people with a learning disability to be involved in activities within the FE sector. This provision points the way towards the positive outcomes that might be achieved if such opportunities were more widespread and consistently available. (55, 87, 88)

Day Services

5.8 Traditionally the majority of school leavers from Severe Learning Disability (SLD) schools have been placed in day centres commissioned by health and social services agencies. The model of such provision has evolved over the years from an industrial/workshop philosophy to a social education model, which emphasises the development of social and life skills. More recently some centres are moving towards becoming resource centres where in-house attendance is combined with involvement in community activities. Concerns about the place of day centres in the service framework of the future led to the 4 Health and Social Services Boards to commission a wide-ranging review, the outcomes of which have informed the Equal Lives Review. (56) The main issues and concerns are:

- in 2002 an estimated 4,000 people were registered with day centres/training centres and workshops. This represents around 70% - 75% of men and women with a learning disability who live in their own accommodation or with family carers.
- 77 centres in Northern Ireland provide a service to men and women with a learning disability aged between 16 and 87 years. The profile of those using the centres includes people with

profound disabilities, those with an Autistic Spectrum Disorder, people with severe challenging behaviours and a growing number of individuals with dementia.

- demand for places exceeds supply. An estimated 180 children with severe and profound learning disabilities leave school each year. If all were to be accommodated in day centres an increase of around 20% in places would be required over the next 5 years with an additional cost of approximately £5.5 million.
- day centres have provided a valuable service to carers who have welcomed the respite for them and the opportunities provided for their son or daughter. However, they have also identified inadequacies including shorter opening hours, transport problems, and the need for more individualised planning.
- day centres can heighten the exclusion of men and women with a learning disability and reduce their engagement with the wider community.

Employment

5.9 Many men and women with a learning disability aspire to having a job and increasing numbers of parents share this aspiration for their teenage sons and daughters. The development of vocational training and the introduction of Supported Employment to Northern Ireland have opened up new possibilities for achieving these aspirations.

- Department for Employment and Learning's Disablement Advisory Service provides assistance to people with a disability to access employment. Programmes on offer include Access to Work, Employment Support, Job Introduction Scheme and New Deal for Disabled People. Mainstream programmes like Jobskills and Worktrack are also available. Significant numbers of young people with a learning disability enter the Jobskills Programme.

- Access to these programmes can be limited by factors such as admission criteria, outcomes required, duration of the programme and the pattern of provision.

- There has been considerable growth in Supported Employment in Northern Ireland over the last decade. The Northern Ireland Union of Supported Employment has over 15 non-statutory agencies in its membership and many other day centres are involved in this work. A number of other approaches to securing paid work have also developed including vocational training and social enterprises. Evaluations of such schemes have evidenced the benefits to individual participants although few of the trainees had made the transition to paid work. (89, 90). European monies from either the Building Sustainable Prosperity or Peace programmes have funded most of this provision. Urgent consideration needs to be given to mainstreaming the funding and the learning.

- A range of external factors impinge on the potential for men and women with a learning disability gaining employment including inflexible rules in relation to benefits, absence of clear intra-agency partnership, low expectations and a disparate reliance on health and social services funding. Difficulties in the reinstatement of benefits and the fact that wages earned may be lower than benefits received means that people may be reluctant to seek paid employment. This was seen as a major barrier to people with a learning disability accessing employment.

- The Department for Social Development has a role in clarifying what currently exists and considering how to make realistic alternatives to benefits work for people with a learning disability.

Transport

5.10 Issues and concerns have been raised to the Equal Lives Review about barriers to work and leisure opportunities arising from inadequate transport provision. This includes:

- the particular transport needs of people with a learning disability in rural areas

- the introduction by the Department for Regional Development (DRD) of reduced charges on public transport for people with a learning disability is a very welcome development. Similar reductions for their supporters are being considered.

- provision of transport within health and social services day services consumes over 25% of the total budget. As a consequence of the locations of many day centres, individuals can spend very lengthy periods being transported to/from centres with only 20% of centres able to transport most of their attendees from home to centre in less than 30 minutes.

- given the emphasis on facilitating people to use transport and enabling people with affordable, accessible transport, there also needs to be an emphasis on accessible transport for those with significant needs/complex needs. The cost of buying a suitable vehicle with appropriate modifications to enable a person with a learning disability to travel whilst seated in their wheelchair, whether through Motability or privately, is prohibitive for many families.

- a number of services have developed innovative independent travel training schemes, which have increased the capacity of individuals to make fuller use of public transport.

Leisure

5.11 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.

- In a study in 2003 the researchers interviewed the parents of over 50 school-leavers from 2 special schools for pupils with severe learning disabilities in Northern Ireland. Three in five of the young people (58%) were reported to have no friends of their own. 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 and for more sports and leisure activities. (63)
- A similar picture emerges for adults. In a 2002 study over 2 in 5 people reported having no friends outside of the day centre they attended and 4 was the most that any one 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. (91)

- A study of 65 persons resettled from a long stay hospital in Northern Ireland into nursing home and residential care found that only 14 people (21%) had regular or frequent contact with friends outside of the residence. This included contact with people in day centres. Only 5 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 4 weeks was 5.6. However, people living in nursing homes had a significantly lower mean score (3.1 activities) than those in residential (5.8 activities) or community homes (7.4 activities). (92)
- Overall people with a learning disability tend to lead more sedentary lifestyles than the general population, performing significantly less than the minimum levels of physical activity recommended by the Department of Health. Levels of obesity appear to be rising among adults with a learning disability in Northern Ireland. (93)
- People with a learning disability often express dissatisfaction with their community, recreation and leisure activities. 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, nightclubs, bars and restaurants and the lack of a companion - befriender - to accompany them. (1)
- Many family carers are also concerned about the lack of leisure opportunities. (56) 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 disability
  - 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.
- 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 main service innovations in this area have 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. (94)
- 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.

5.12 Despite the fact that access to social and leisure opportunities is extremely limited for many men and women with a learning disability relatively few resources have been expended in this area. Greater attention to developing people's social networks could pay dividends in other ways by reducing the possible consequences of social isolation including challenging behaviours and depression.

Personal Relationships

5.13 Meaningful relationships, including marriage, and expression of one's sexuality contribute greatly to people's quality of life. The sexual expression and developing sexuality of people with a learning disability is often seen as problematic and not a normal part of growth and development. This ignores the person's rights and the benefits to be gained.

- The subject of relationships and sexuality and the social skills required to form appropriate relationships receive insufficient attention at home, at school and in other service settings.

- The changes in the life stages of people with a learning disability are often not recognised. There is a marked lack of sex education for men and women with a learning disability and lack of guidelines for staff who provide sex education.

- Life stages and general sexual and reproductive health care is not provided. For women in particular issues are not adequately addressed in relation to premenstrual syndrome, cervical and breast screening, sexual health screening, menopause.

- Sexual orientation and preferences often go unnoticed and undetected or attributed to lack of experience, choice or environmental influences.

5.14 Staff members who participated in a consultation exercise as part of the Equal Lives Review highlighted a number of issues pertinent to supporting sexual expression that they feel unable to resolve because of lack of clear legislation, policy and guidelines. These included:

- participants working in residential care settings who expressed feelings of frustration around being willing to support clients in their sexual expression but being hampered by how current legislation is interpreted and implemented through policy

- a perceived need for greater clarity between the Mental Health Order, Sexual Offences Act and Human Rights Act, in relation to service users' rights around sexual expression and the process used to assess capacity to consent

- a need for ongoing training, supervision and support to develop understanding and competencies at different levels of intervention, mostly around inappropriate touch/abusive behaviours

- policies are now more likely to acknowledge the rights of people with a learning disability around their sexuality and sexual expression, however, there is a lack of clarity around whether service users' rights are prioritised above parents' rights and the legal position regarding parents' rights i.e. if there is a clash between the individual's wishes and parents' wishes, whose views should be prioritised?

- balancing rights, responsibilities, vulnerabilities and risk in this area is complex and hampered by apparent lack of clear direction as to the parameters within which staff should work at a practice level.

5.15 We anticipate that the ongoing work of the Legal Issues Committee and of the Office of Law Reform on mental capacity will assist in resolving some of these issues.

5.16 There is a lack of support, education and training for parents, to enable them to identify emergent issues and gain knowledge and skills in supporting their children. Many parents struggle with their own values and beliefs around sexual expression and the desire of young people and adults with a learning disability to form sexual relationships. The following issues have been expressed by parents:

- fears and concerns around lack of support for children particularly when, during times of transition from primary to post primary education, they are seeking to keep their children in mainstream education
- education around appropriate sexual expression. Parents often feel unable to discuss problems with others and are unable to identify appropriate means of support.
- accessing appropriate information to support them to provide sex education for their sons or daughters.

Action Required

5.17 To address the wide-ranging concerns that have been identified a strategy is required that reduces the barriers to community integration and ensures equity of opportunity and social inclusion. Given its responsibility to promote lifelong learning, further education and increased employability the Department for Employment and Learning has a key role in developing such a strategy.

5.18 In Chapter 12 we set out proposals for new organisational arrangements that should oversee the implementation of these recommendations at both a regional and a local level.

5.19 The starting point for improvement must be the work undertaken at the transitions phase. It is alarming to note that despite effective transition planning being a mandatory requirement, so many young people have unsatisfactory experiences during the move from school towards adulthood. This is a key period when opportunities exist for pioneering a new style of service for a young generation of people rather than pursuing an automatic progression from special school to day service. Parents and young people should be targeted and offered a co-ordinated transitions programme that prepares for the transition to adulthood. This must be accompanied by a transitions plan that outlines the individual's interests and needs including vocational training, education and employment, health profile, social supports, leisure, friendships and social development. Transitions planning should begin at 14 years of age and if required appropriate transitions support available until 25 years. In order to achieve this it is recommended that a Transitions Service is developed for each population of 100 - 120,000 which will work with approximately 60 young people to ensure that the transitions programme and plan are addressed by relevant agencies. **(Recommendation 14)**

5.20 It is clear that transitions planning should not occur in isolation of other initiatives designed to increase opportunities for employment, education and other meaningful daytime activities, if we are to avoid falsely raising expectations. Transition Workers will require close working relationships with a number of agencies including schools; special education officers; the Careers Service; vocational training and employment service providers; the volunteer bureaux; voluntary and community groups, as well as employers and the business community. Current work by the Inter Departmental Group on Transitions will provide a positive steer in this regard. The key will then be local arrangements that are robust and reflect shared planning and ongoing monitoring of provision.

5.21 Provision in FE colleges needs to be fundamentally reviewed and tailored better to meet the need of students with a severe learning disability. Education providers must meet their obligations under the Special Educational Needs and Disability Order (SENDO) to ensure that existing policy, teaching, curriculum and facilities ensure that young people with a learning disability are treated as favourably as others in relation to accessing provision. This includes ensuring that there is a culture of inclusion; that prospectuses and other information produced is accessible and that appropriate learning and financial support is available. In addition it is recommended that the FE sector develop new programmes specifically designed to meet the Lifelong Learning needs of men and women with a learning disability. Particular attention needs to be paid to school leavers amongst whom the specific needs of those leaving at 16 should be noted. We suggest that around 270 fulltime places are required in future years for school-leavers and we recommend a further 300 whole-time equivalent places for older students. **(Recommendations 15, 16)**

5.22 There is a need for a radical reconfiguration of existing day service provision based on a progressive shift towards a resource model. As alternative provision develops there should be a reduction in the numbers of people who attend day centres on a full-time basis. It is anticipated that centres will in future be providing a service to men and women with increasingly complex needs who should also be enabled to access opportunities for community integration. Day centres will need to explore the need for developing sites for meeting the particular needs of people with an Autistic Spectrum Disorder and older people. We believe that the potential for day centres to be used as resources to the community is particularly underachieved at present. Partnership with community and voluntary groups should be explored particularly for the development of evening and weekend access to the centres to facilitate other services and community groups.

5.23 The modernisation of day centres will require reallocation of existing resources and additional investment in physical infrastructure and human resources. In order to stimulate the modernisation agenda each day centre should be required to produce a development plan in partnership with attendees, family carers and potential provider partners. The development plan should address as a minimum issues of:

- location
- buildings
- service functions and activities
- people served
- staffing
- transport
- payments made
- developing links to community and other providers
- provision for people with complex needs.

5.24 Future Department of Health, Social Services and Public Safety investments in day services should be targeted at the development of other supported placements including voluntary work and leisure opportunities. There are different models of achieving this and diversity of provision should be encouraged to promote innovative and creative approaches. **(Recommendation 17)**

5.25 In order to enable the proposed reconfiguration of day services and to promote access to the labour market for men and women with a learning disability it is recommended that supported employment services are developed across Northern Ireland. The Disablement Advisory Service should take the lead in reviewing the existing specialist employment provision including the use of its disability programmes by people with a learning disability. In particular the aim should be to have such services available in each area serving a population of 100-120,000 persons. We welcome the recent initiative of the Department for Employment and Learning to reviewing its employment services for persons with disabilities, including those with a learning disability. **(Recommendation 18)**

5.26 The public sector is a major employer in Northern Ireland. Public bodies could play a key role in addressing the barriers to employment experienced by men and women with a learning disability. Attention should be directed towards the process of recruitment for posts in the public sector including the routes into work, reviewing job descriptions, creation of more part-time posts, process used to attract individuals to apply for a vacancy and selection and interview processes.

5.27 The development of policies and practice in these areas in terms of making reasonable adjustments as defined in the Disability Discrimination Act 1996 would help promote equality of opportunity in a most positive manner. **(Recommendation 19)**

5.28 Mainstream vocational training provision could do more to accommodate the needs of school leavers and adults with a learning disability wishing to enter the labour market. The impact of admissions criteria, course content and outcome related funding on access by people with a learning disability should be examined. Improvements should be made in support provided to participants and the training of staff. **(Recommendation 20)**

5.29 The limitations posed by existing transport provision have curtailed access to educational, employment and leisure opportunities. A determined effort is required to ensure that these barriers are removed. There is scope to more actively promote independent travel on public transport and on foot. This should be planned with the support of the family and must feature in schools and college curricula as well as in other support services. In addition those charged with responsibility for public transport must ensure that the particular needs of men and women with a learning disability are incorporated in their strategies. **(Recommendations 21, 22).**

5.30 With the emphasis on facilitating people to use transport and enabling people with affordable, accessible transport, there also needs to be an emphasis on accessible transport for those with significant needs/complex needs. The Motability Scheme requires reviewing to ensure an appropriate, affordable solution for those who need to travel in their wheelchair along with other family members. **(Recommendation 23)**

5.31 Leisure and recreation schemes should be promoted and co-ordinated at District Council level. An audit should be commissioned of leisure and recreation facilities, societies and clubs within their area that serve the wider community as well as people with disabilities. This Directory should be maintained by District Councils and widely circulated to all service providers (including residential services) and family carers. A central point should be created or identified for recruiting volunteer helpers and drivers. Different schemes within District Councils should have shared access to a minibus or people-carriers. Seed monies should be available to initiate new schemes. **(Recommendation 24)**

5.32 Now that all services are expected to have policy guidelines in place on sexuality and personal relationships, there needs to be concerted efforts across all services to make available opportunities for education on these issues and on sexual health. This should be done with the knowledge and support of family carers, but they should not have a sanction on their relative's participation if that is his or her wish. (**Recommendation 25**)

5.33 The issue of bullying that is commonly reported by self-advocates needs to be proactively addressed both in specialist services and the wider community. In the latter instance, the greater involvement of people with a learning disability in educating senior pupils in primary schools and secondary school students has increased the students' awareness of the hurt they cause. Equally people with disabilities should be encouraged to exercise their rights to make complaints to the police or other relevant authority. It should be noted that the draft Criminal Justice Order includes disability within its definition of the grounds for hate crimes. **(Recommendation 26)**

5.34 Objectives 3 and 4	**Recommendations**
Recommendation 14	That Transition services are established for all young people who have a statement to support parents and young people to develop a transitions plan and ensure recommendations are carried through. Careers advice restructuring should support this proposal and provide an ongoing support to 22 years.
Recommendation 15	The Department for Employment and Learning will ensure that revised funding arrangements are in place so that FE Colleges are able to increase significantly the number of full-time places available to students who have a Statement of Severe Learning Disability, to undertake a 3 year accredited course.
Recommendation 16	In order to afford lifelong learning opportunities the Department for Employment and Learning should ensure that revised funding arrangements will enable more part-time places to be created in FE for older students. Access to FE by people with a learning disability should be monitored and we welcome the intention of the Department for Employment and Learning to do so.
Recommendation 17	By March 2007 each Health and Social Services Trust should have produced a costed Development Plan for each day centre they provide or commission.
Recommendation 18	The Department for Employment and Learning, in consultation with other relevant Departments, should promote the introduction of dedicated Supported Employment services across Northern Ireland.
Recommendation 19	Public sector employers should review their recruitment practices, as required by equality legislation to open up employment opportunities for men and women with a learning disability.
Recommendation 20	Department for Employment and Learning should review the use of its employment, skills and disability programmes by people with a learning disability to remove structural barriers to participation and identify how they could promote better outcomes.
Recommendation 21	Department of Education and Department of Health, Social Services and Public Safety should ensure that young people with a learning disability are equipped with skills to use public transport where possible through appropriately targeted independent travel training programmes. Where possible these should become part of the curriculum and continuing education plans for young adults.

Recommendation 22	Department for Regional Development should ensure that the regional transport strategy ensures that people with a learning disability can access local transport.
Recommendation 23	The Motability Scheme requires reviewing to ensure an appropriate, affordable solution for those who need to travel in their wheelchair along with other family members.
Recommendation 24	Access to local leisure and recreational services should be promoted and co-ordinated led by District Councils.
Recommendation 25	Personal relationships education should be available in all services for people with a learning disability with training offered to staff and support to parents.
Recommendation 26	OFMDFM should co-ordinate a policy initiative to reduce the likelihood of bullying experienced by people with a learning disability, both in specialist settings and the wider community, notably schools. The development of anti-bullying strategies would be a positive first step.

ACCOMMODATION AND SUPPORT

Chapter 6

> “ ” *Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative and recreational activities. If the stay of a disabled person in a specialised establishment is indispensable, the environment and living conditions therein should be as close as possible to those of the normal life of a person of his or her age.* **UN Declaration on the Rights of Disabled Persons 1975 (51)**

6.1 Shelter and care are basic human needs. Where we live and with whom we live, help to define us as individuals and give us status. The location of our homes often determines the extent of social inclusion that we experience. During much of the last century those people with a learning disability who could not live with their families had to live on a long-stay basis in hospital accommodation or residential facilities. The most recent Review of Policy for People with a Learning Disability (7) clarified as a Government priority, the need to resettle people who were living in hospital. In many cases the accommodation that replaced the hospitals retained many of their features; most obviously sizeable groups of people who were unrelated to each other living together in hostels, care homes and nursing homes with little engagement with local communities. More recently a wider range of housing options have been developed based on more individual responses and located in ordinary buildings in the community. However, the emphasis on resettlement in Government policy has resulted in an imbalance between efforts to secure alternative housing for people living in hospital and the lack of development of supports to those living with their families. Future housing strategy must take account of population trends that evidence that a growing number of people will require alternative housing options and the need to alleviate pressures on family carers who currently provide accommodation for the majority of people with a learning disability in Northern Ireland.

Objective 5 To ensure that men and women with a learning disability have their homes in the community, the choice of whom they live with and that, where they live with their family, their carers receive the support they need.

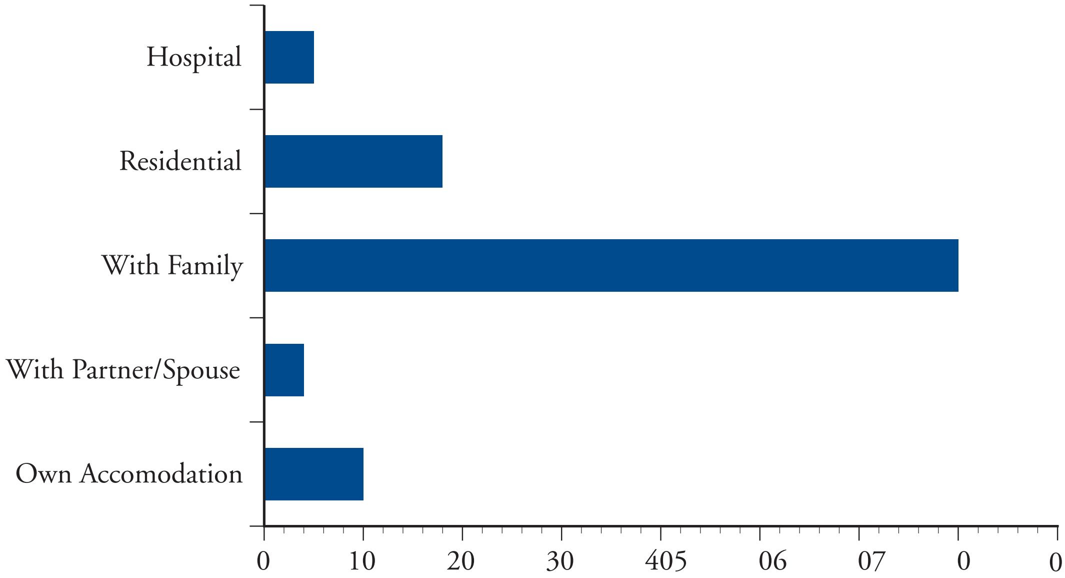
Objective 6 To ensure that an extended range of housing options is developed for men and women with a learning disability.

Where Do People with a Learning Disability Live?

6.2 Nearly all children (up to 19 years of age) live in family homes either with natural, adoptive or foster parents. (15) Accurate figures are not available for all of Northern Ireland, but in a study in the EHSSB area 34 children were living in some form of residential accommodation and 26 in foster care arrangements. Together these represent 2% of all children known to Health and Social Services Trusts in that area. (73)

6.3 Figure 5 shows where men and women with a learning disability are living.

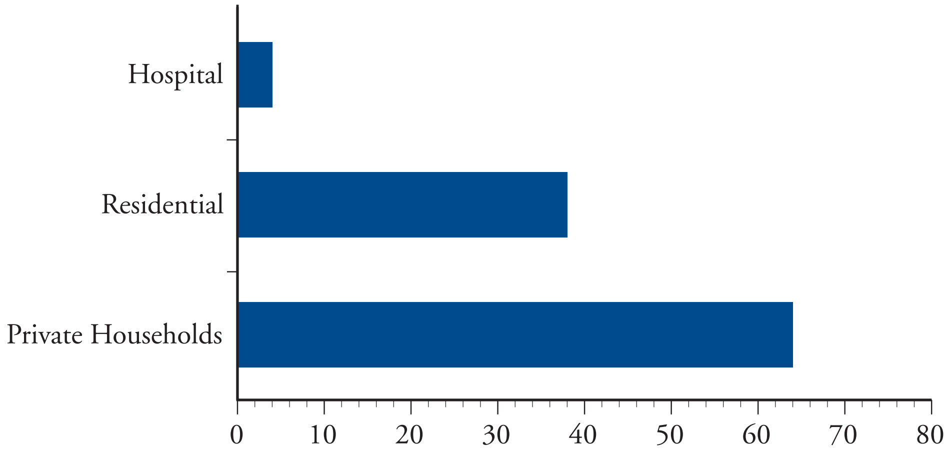
Figure 5: Percentage of adults in different forms of accommodation in Northern Ireland in 2003 (N=7,970) (15)



6.4 As figure 5 shows the majority of people live with family carers although a small proportion have their own accommodation. Around 450 live in 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.

6.5 Comparable figures for Great Britain are given in Figure 6.

Figure 6: Percentage of adults in different forms of accommodation in Great Britain in 1999 (95)



Issues and Concerns

6.6 The main concerns with current arrangements that were highlighted to the Equal Lives Review relate to the position of men and women with a learning disability living long-stay in hospitals, the reliance on large group living arrangements, pressures on family carers and the barriers to developing an appropriate range of housing options.[7]

- Although the number living in learning disability hospitals has been declining since the 1980s, in 2003 it was estimated that 455 men and women with a learning disability had no home outside a hospital: Muckamore Abbey Hospital 300, Longstone Hospital 115 and Stradreagh Hospital 40. (15) This is in spite of the fact that hospital resettlement has been the cornerstone of Government policy in Northern Ireland since 1995. The average age of people living in hospital in Northern Ireland is 49 years. Many have a severe learning disability and more complex needs. They typically live in ward-style accommodation. Few have their own bedroom.

- Research into the resettlement programme has highlighted that people were relocated largely into large group settings with little use being made of more individualised options, such as supported living options. There is also growing concern about what has been termed the *new long stay population* namely those men and women with a learning disability admitted to hospital for assessment and treatment, but who have remained in hospital owing to the absence of a suitable community alternative. Studies have placed this group at between 11 and 15 % of those admitted. (46)

- Approximately half of the remaining men and women with a learning disability who live outside the family home live in registered residential care homes (950 individuals). On average the homes

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[7] Unless otherwise stated the evidence cited in this section is drawn from a series of reports prepared for the Northern Ireland Housing Executive and the 4 HSS Boards by Professor Roy Mc Conkey and colleagues (96, 97, 98, 99)

accommodate 20 individuals. A further 29% live in registered nursing homes. Recent research indicates that approximately 220 men and women might be more appropriately accommodated in supported living options.

- A growing number of people (19%) do live in supported living arrangements where typically they have tenancy agreements and live on their own or with one or two other persons and have support from staff including 24-hour cover if needed. Of those living in these 3 forms of accommodation, the majority came to their present home from living in a hospital (42%) and a further 25% from another residential facility. Only 34% came from the family home.
- Concern has been expressed at the lack of consistency across Northern Ireland in terms of the types and level of provision, which may indicate service inequities. The Northern Health and Social Services Board had the highest proportion of people in nursing home accommodation (46%) as compared with 22% in the Eastern Health and Social Services Board. The Eastern Board had the highest level of people in supported living arrangements (31%) as compared with only 4% in the Western Board and 3% in the Southern Board.
- Most people live with family carers; usually their parents. Nearly one third presently live with a single carer and over 25% with carers aged over 65 years. Around one in 6 carers were rated as being in poor health. These are all risk factors that make present care arrangements vulnerable.
- Families with a disabled member experience far greater problems with their housing than families with non-disabled members. In one study 9 out of 10 families reported at least one difficulty with their housing and many reported multiple problems. (100) Families on low incomes experienced most problems. These include the need for better bathroom facilities and requirements for extra storage space. The report noted that only 10% of families had received assistance from statutory agencies in order to address their housing needs. Families find the process of obtaining grants to improve their homes is complex and time-consuming and often the monies made available are insufficient to cover the cost of the adaptations that are required.
- Carers of people with complex physical and health needs felt particularly unsupported with very limited opportunities for respite breaks and a lack of choice as to alternative care arrangements when they can no longer cope. (2)
- Only a small proportion of people have their own house (around 10%) or live with a spouse/partner (3%).
- More recently a small number of agencies have developed Adult Placement Schemes where families are actively recruited, supported and paid to provide short breaks or long-term homes for selected individuals. Whilst these developments have to date been used successfully in Northern Ireland primarily for short breaks, there is room for further development of the model for the provision of permanent homes. (101, 102)

Futures Planning

6.7 The Equal Lives Review has also been presented with a number of issues and concerns linked to planning for future provision that will need to be incorporated in housing strategies developed to address emerging and current needs.

- To date most of the planning has related to the resettlement of people from long stay hospitals. This will continue to be an issue with over 400 people still requiring a move to accommodation in the community. However, the predominance of the resettlement agenda over recent years has had adverse effects in terms of the lack of attention paid to planning for the future housing needs of those who live with families, many of whom are in housing arrangements that are vulnerable to breaking down owing to illness or family crisis. In addition, the type of accommodation favoured during the resettlement programme is not suitable for future needs as men and women with a learning disability increasingly aspire to accommodation arrangements that are more independent and closely integrated into their communities. Large scale, group environments will not meet these aspirations, which will increasingly in the future be driven by awareness of human rights and concepts of social inclusion.

- In addition to those currently living in hospital it is estimated that approximately 1600 persons may require alternative accommodation and/or support arrangements in the coming 5 to 10 years. Of these around 170 are likely to be required in the next 2 years with half of this figure needed in the Eastern Health and Social Services Board area. The amount and type of support varies across individuals, but could involve assistance with personal care, medication, household activities, community participation, budgeting, inter-personal relationships and behaviour management.

- We have identified a number of issues with current administrative systems that threaten the development of more appropriate housing and support options for people with a learning disability:

  - there has been a lack of bridging finance to the same extent as was available in Great Britain to enable people to be resettled from hospitals

  - as yet no commitment has been given to the resettlement of all long-stay patients by a designated date

  - dowry systems are not in place so that the money can follow the resettled person in perpetuity

  - care management procedures as they presently operate, coupled with lack of finance and community options, constrain staff from promoting options for more independent living arrangements and planning for them over a longer time frame

  - men and women with a learning disability, irrespective of where they presently live, are not encouraged by their carers to have their name placed on the waiting lists for public sector housing if a change in accommodation is likely to be required

  - the Equal Lives Review has been made aware that the Common Selection Scheme now operated by the Northern Ireland Housing Executive could make it more difficult for people with a learning disability to access housing that is appropriate to their needs

  - revenue costs for complex needs housing schemes must be secured at the same time as capital costs are committed. This will guarantee that the places are allocated to the persons for whom they were planned. However, revenue allocations by both the Department of Health, Social Services and Public Safety and the Department for Social Development (DSD) are done on an annual basis which prevents planning commitments being given for capital developments that may take up to 3 years to complete.

Action Required

6.8 We propose that the following service principles and aspirations should guide the development of future housing and support options for people with a learning disability. They arise from existing legislation, recent research findings undertaken with this client group and recognised good practice already taking place in Northern Ireland and elsewhere in these islands. They also take cognisance of recent and future legislative changes such as the Disability Discrimination Act and the proposed introduction of a Bill of Rights.

- People with a learning disability have the right to the same range and standards of accommodation that is available to their non-disabled peers.
- They have the same rights as other citizens in obtaining tenancies in public housing, in buying and inheriting houses and in claiming housing and other support benefits to which they are entitled. This includes access to Direct Payments and the Independent Living Fund.
- At present, families provide homes and support for the great majority of people with a learning disability in Northern Ireland. Moreover it is the wish of many people to continue living within the family. Hence families should be supported in continuing to provide housing and support to their relatives as long as both parties wish this to happen. This support should include the provision of housing adaptations, of domiciliary supports and of short breaks.
- People with a learning disability should be enabled to remain in their neighbourhoods if they want to when family carers are no longer able or available to look after them. They should be assisted to continue living in the family home by having tenancies transferred to them; participating in the right-to-buy schemes or the ownership of the house being passed over to them. Domiciliary supports should be made available to the person with a learning disability as well as to family carers.
- Meeting the accommodation and support needs of people with a learning disability is not just the responsibility of health and social services. Hence Health and Social Services Boards and Trusts must work in partnership with a range of statutory and non-statutory housing and social care agencies in order to fulfil these needs.
- A range of different types of accommodation and support services should be available within Northern Ireland so that services can be better tailored to the needs of individuals and to provide for an increased element of choice. People with a learning disability, their relatives and paid carers should be informed about the range of accommodation and support options that are available. This should be done in accessible formats.
- When demand for accommodation and support services exceeds supply, the allocation of these services should be done in a transparent and equitable manner. Applicants, their family carers and advocates must be kept fully informed throughout.
- People should not live in hospital accommodation. Some may have to be admitted for short periods (of up to 6 months) of acute assessment and treatment, but no one should remain there for long periods (12 months+) due to their specialist needs. Everyone should have a home address to which they will be discharged.

6.9 Resettlement of long-stay patients from hospitals within the context of supported living principles must be progressed as rapidly as possible. By June 2011, all people living in a learning disability hospital should be relocated to the community. Funds need to be provided to ensure that on average 80 people will be resettled per annum over the 5-year period from 2006 to 2011. **(Recommendation 27)**

6.10 In order to address the concerns raised about the potential for developing a new long stay hospital population all commissioners should ensure that they have arrangements in place to provide emergency support and accommodation for persons with a learning disability. Learning disability hospitals should not provide this service from 1 January 2007. **(Recommendation 28)**

6.11 Objective 5 Recommendations

Recommendation 27	By June 2011, all people with a learning disability living in a hospital should be relocated to the community. Funds need to be provided to ensure that on average 80 people will be resettled per annum over the 5-year period from 2006 to 2011.
Recommendation 28	With immediate effect, all commissioners should ensure that they have resourced and implemented arrangements to provide emergency support and accommodation for persons with a learning disability. Hospitals will not provide this service from 1st January 2008.

6.12 In line with the thrust towards more normal, individualised housing options for men and women with a learning disability there is a need for both a wider range of supported living provision, to include adult placement services, and to address the deficiencies identified in large-scale group living environments. New care standards coming into force over the next 3 years will require upgrading of much current provision. This is not only to improve the quality of life of existing residents, but also to secure better quality provision for future users of these accommodation options. We propose that in future all new-build accommodation provided for people with a learning disability should be for no more than 5 individuals - preferably less - within the same building. This accommodation should take the form of lifetime, barrier-free homes, i.e. homes that can provide security of tenure for the tenants and be designed in such a way as to be suitable for meeting the needs of current and potential physical disabilities. In order to assure equity of provision it is also proposed that by January 2013 all accommodation provided for men and women with a learning disability and aged under 60 should be in households of 5 or less individuals. **(Recommendations 29, 30)**

6.13 In order to meet the emerging needs identified an additional 100 supported living places per annum for the next 15 years should be developed to enable people to move from family care without having to be placed in inappropriate settings. **(Recommendation 31)**

6.14 These proposals will require close collaboration with the NI Housing Executive, Department for Social Development and health and social services agencies. There should also be active engagement with personnel from the Social Security Agency at both regional and local levels. Mechanisms should be put in place to engage with District Councils, Local Health and Social Care Groups and community organisations in the development of local initiatives. In particular funding mechanisms and planning cycles urgently need to be addressed in order to enable the extensive programme of work that is required. The capital and revenue cycles of both Department of Health, Social Services and Public Safety and Department for Social Development need to synchronise for Supporting People schemes. **(Recommendation 32)**

6.15 In particular when considering the needs of people with more profound and multiple disabilities the potential for technological advancements in maximising opportunities for independence needs to be more fully harnessed. Housing planners and service providers should improve their awareness of such developments and their application within future housing strategies. **(Recommendation 33)**

6.16 The Equal Lives Review has highlighted the low level of home ownership amongst men and women with a learning disability in Northern Ireland. It should be clarified if Supporting People monies can be used to support people who are owner-occupiers. There is considerable scope for meeting at least some of the emerging housing needs through Supporting People to either purchase their own homes or to take over the ownership of property left to them by families. **(Recommendation 34)**

6.17 Improved supports need to be given to family carers to enable people to continue living with their families. This includes improved short break provision; extension of home based, floating support services to maintain people in family homes; support for other family members to take over the caring role from ageing parents if they wish to and improvements to the process of accessing housing adaptation grants. **(Recommendation 35)** The Department for Social Development and the NI Housing Executive should ensure the increased use of floating support linked to an individual's needs rather than overly relying on accommodation based schemes. This would make it easier for people to move to more suitable accommodation as their needs change. **(Recommendation 36)**

6.18 Objective 6 Recommendations

Recommendation 29	With immediate effect, all new housing with support provision for people with a learning disability should be for no more than 5 individuals with a learning disability - preferably less - within the same household.
Recommendation 30	By 1 January 2013 all accommodation for people with a learning disability under 60 years of age should be for no more than 5 people.
Recommendation 31	An additional 100 supported living places per annum for the next 15 years should be developed to enable people to move from family care without having to be placed in inappropriate settings.
Recommendation 32	Department for Social Development and Department of Health, Social Services and Public Safety should develop clear assessments of future housing needs for people with a learning disability including those who currently live with their families and agree a continuous 3 year funding strategy to resource housing and support arrangements.
Recommendation 33	Housing planners should accumulate and disseminate detailed knowledge on the range of assistive technology that is available to enrich the capacity of people with a learning disability to lead more independent lives in the community.
Recommendation 34	A strategy should be developed by the Department for Social Development to increase opportunities for people with a learning disability to own their own homes where this is a safe and appropriate option.
Recommendation 35	Procedures and criteria for applying for Disabled Facilities Grants should be revised to tackle inconsistencies, reduce bureaucracy and reduce the hidden costs to carers.
Recommendation 36	Department for Social Development and the NI Housing Executive should establish mechanisms to ensure the increased use of floating support linked to an individual's needs rather than overly relying on accommodation based schemes.

HEALTH AND WELL BEING

Chapter 7

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity **World Health Organisation 1946 (103)**

Health is a fundamental human right **DHSSPS 2002 (104)**

7.1 An increasing number of people with a learning disability are living longer and healthier lives. Greater numbers of children with complex health needs and multiple disabilities are surviving into adulthood. Increasingly people with a learning disability who experience mental health problems are living in local communities rather than having their homes in specialist hospitals.

7.2 In order to ensure that people with a learning disability enjoy the benefits of such changing circumstances, commissioners and service providers will need to actively ensure that there is equity of access to the full range of healthcare provision enjoyed by the general population. This is now clearly enshrined in human rights and equality legislation. Evidence presented to the Equal Lives Review demonstrates that there are both high levels of unmet health needs and deficiencies in the current systems for ensuring that the physical and mental health needs of people with a learning disability are effectively addressed.

7.3 In this chapter we will outline the key issues and concerns relating to the physical health of people with a learning disability. A coherent strategy is then proposed to address the concerns based on the Equal Lives Values and those principles that currently inform public health policy. Chapter 8 will address issues related to mental well-being and challenging behaviours.

Objective 7 To secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability.

Issues and Concerns

7.4 Research has consistently confirmed that the life expectancy of people with a learning disability has increased markedly over the last 60 years. One study reported an increase in the average age of death between 1931 and 1995 of 53 years for men (from 14.9 - 67.2 years) and 47 years for women (from 22 - 69.2 years). (105)

7.5 However, the research evidence also indicates that people with a learning disability have higher mortality rates than people in the general population. (106, 107)

7.6 Some people with a learning disability are at higher risk of physical ill health arising from problems associated with particular conditions or syndromes: (42, 108, 109, 110)

- physical and sensory impairments are more frequent amongst people with a learning disability
- they may also develop further difficulties related to cardiovascular problems, resistance to infections and their immune systems
- there is an increased prevalence of physical and sensory impairments amongst people with a learning disability
- there is an increased prevalence of epilepsy which occurs within 25% of people with a learning disability and 1/3 of people with profound learning disability
- there are significantly higher levels of obesity
- increasing numbers of people with a learning disability require intensive nursing care and technological support owing to complex health needs, have higher risk of infection or respiratory difficulties.

7.7 On occasions individuals may be so vulnerable and have such complex needs that they lack full insight into the degree of support required to keep themselves physically and mentally well. The Legal Issues Committee is addressing this issue in detail in the context of capacity.

7.8 Northern Ireland studies were at the forefront in identifying the high levels of undetected health problems amongst people with a learning disability, some of which are easily remedied such as impacted ear wax. Often the problems remain undetected for long periods until they become serious and more obvious.

7.9 The oral health of people with a learning disability is worse than the general population with poorer oral hygiene, higher untreated diseases and more extractions. (111, 112) This was an area of particular concern to family carers during consultation events (2) and is the subject of a separate review being undertaken by the Department of Health, Social Services and Public Safety.

7.10 In December 2004 the Disability Rights Commission launched a formal investigation into health inequalities experienced by people with long-term mental health problems and people with learning disabilities in England and Wales. The investigation, which is titled Equal Treatment - Closing the Gap, has been launched because of the overwhelming weight of evidence pointing to disparities in health outcomes amongst people with learning disabilities and people with long-term mental health problems. Put simply, a lot of evidence points to the fact that these groups of people have higher morbidity and mortality rates than the overall population, and not always due to reasons related to their disability. Therefore the Disability Rights Commission has decided to use its powers to undertake formal investigations to instigate a comprehensive enquiry into this issue.

> *My daughter has been waiting since January (11 months) to get 2 bad teeth removed. No reasons have been given to me to explain why the delay. She is suffering and in constant pain. She should not have to go through this.* (2)

7.11 Primary care services are the first point of contact for many family carers and people with a learning disability in seeking help with health concerns. For many the family GP has a very significant role. Where a GP has a good relationship with families, s/he can have a very positive influence on the healthcare experiences of both the family and the individual with a learning disability. (2) However, while this is the case in many instances, a number of concerns have been identified.

- Many people with a learning disability make less use of their GP. (113) In a study in the Western Health and Social Services Board area 44% of GPs and 63% of nurses reported that people with a learning disability used the practice less often than other patients. (114)

- GPs can have limited confidence about their role in meeting the health needs of people with a learning disability. (113, 115)
- There is a limited uptake of health screening by people with a learning disability. (116, 117)
- Difficulties have 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 such purposes. In a survey in the WHSSB area 51% of GPs reported that they could not easily identify people with a learning disability. (114)
- Confusion exists about the roles and responsibilities between specialist learning disability services and mainstream health services in relation to the health care of people with a learning disability. However, where they do work together health status can be improved. (113)

7.12 In the past people with a learning disability who required hospital treatment arising from a physical health problem were sometimes admitted to specialist learning disability hospitals. The inappropriateness of this practice was recognised and Government policy now emphasises the rights of all to access mainstream health services including acute hospitals. The Equal Lives Review was informed about a number of positive initiatives in Northern Ireland acute hospitals to facilitate people with a learning disability including one hospital making arrangements to reduce waiting times in hospital and the provision of accessible information in another. However, consistent feedback from our consultations indicated that in many instances acute hospital staff require staff from the learning disability service or a family member to be present all the time on the ward when the patient is in hospital. As yet there has been limited study of the extent of contact that people with a learning disability have with acute hospitals or the quality of their experiences.

7.13 Findings from a study in Northern Ireland provide some indication of the position: (118)

- 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 assessments and advance planning
- at admission time limited steps are taken to accommodate the individual abilities and the needs of the person with a learning disability
- people with a learning disability are often excluded from key discussions and decisions 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 communicating and managing 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
- acute hospitals may need to provide ongoing support if treatment is to be completed successfully and to avoid premature discharge
- more effective liaison arrangements between acute hospitals and learning disability services need to be put in place
- there is a need for further training of staff to work with people with a learning disability in acute hospital settings.

7.14 These findings are similar to others, which have been reported by people with a learning disability and family carers from elsewhere in Northern Ireland. (1, 2, 119)

7.15 During the Equal Lives Review we also learnt of many excellent initiatives in Northern Ireland designed to improve the health status of people with a learning disability. These include research, health screening projects, production of accessible health information and health promotion initiatives.

7.16 Unfortunately many of these initiatives have been ad hoc, project based and time limited owing to funding constraints. Therefore, while they have benefited local groups, they have had limited impact on the regional health status of people with a learning disability. (40, 41, 42)

7.17 Despite increased emphasis on health promotion issues in Government and health service policies there is little evidence of specific targeting of people with a learning disability within Northern Ireland. This contrasts with the position in England, Scotland and Wales where specific guidance and policy has been produced. (120, 121)

Access to Specialist Services

7.18 People with a learning disability should have access to the wide range of specialist health care services available in the community including neurology services, epilepsy nurse specialists and diabetes nurse specialists.

7.19 The creation of Health Facilitator posts in England has enabled more people with a learning disability to have access to this range of services while supporting such services to develop the necessary skills to meet their needs. Although the term is new, Health Facilitation is not a new concept and can be used to describe anyone who is assisting a person with a learning disability to achieve and maintain good health. Indeed Health Facilitation is a central component of each professional working in any field. However the formal recognition that named Health Facilitators are receiving is new, together with the opportunity to act on a strategic as well as a local level. Health Facilitation evolved from roles developed by carers, practitioners and others who were concerned about improving the health of people with a learning disability through the NHS in order to access the best and most appropriate health care.

Aids To Daily Living

7.20 Evidence presented throughout the Equal Lives Review confirms that there will be a marked increase in the number of children, men and women with complex physical health needs and disabilities.

- Timely access for necessary equipment must occur to prevent long waiting times that often cause extreme physical hardship.
- On average each disabled child in Northern Ireland uses three pieces of specialist equipment each day as an aid to daily living. Families often report long waiting times between assessments and delivery, problems with repairs and needs changing over time not being assessed. Much energy is expended by families in accessing these vital practical aids which can lessen burdens associated with mobility, continence, feeding and sleeping. The absence of these at the right time increases stress on the family unnecessarily. (79)

Action Required

7.21 In 2002 the Ministerial Group on Public Health launched a new public health strategy Investing for Health, which sets out the way forward in making improvements to the health of the population in Northern Ireland. (104) Investing for Health adopted 4 key values:

- health is a fundamental human right
- policies should actively ensure equality of opportunity and promote social inclusion

- individuals and communities should be included fully in decision-making on matters relating to ill health

- all citizens should have equal rights to health, and fair/equitable access to health services and health information according to their needs.

7.22 Whilst the specific health needs of people with a learning disability receive limited attention, it is noted that people with disabilities are entitled to the same access to opportunities as their non-disabled peers. In order to ensure that the outcomes of Investing for Health benefit people with a learning disability, determined action will be required to reduce the inequalities in health and service provision that currently exist.

7.23 An effective strategy should include the following:

- a priority theme of ensuring that the health needs of people with a learning disability are better served by mainstream health services in the first instance

- improving collaboration between primary health care staff and learning disability services

- optimising the contributions of learning disability expertise in achieving health gains but reshaping their contribution to achieve improved health outcomes and access to mainstream services. The role of professionals in learning disability services should develop to enable them to build new relationships with mainstream colleagues, improve the knowledge base of mainstream staff and reshape their contribution to service provision.

- ensuring that the small number of individuals with complex health needs and additional disabilities whose needs cannot be effectively managed by mainstream services receive ongoing and intensive support from specialist professionals to ensure their needs are met

- reshaping the workforce and meeting a wide range of staff training and development needs (This will be explored further in Chapter 11).

7.24 Despite the clear evidence on unmet health needs amongst people with a learning disability limited attention has been paid to these issues in either Departmental or Health and Social Services Board/Trust policy documents. This fails to acknowledge the particular support needs of many people with a learning disability in relation to accessing health care services and health promotion initiatives.

7.25 In order to make a long-term and sustained improvement to the health status of people with a learning disability there is a need for a regional approach to health improvement. This is particularly crucial in view of the evidence that where targeted action has been taken in specific localities, positive outcomes have been demonstrated.

7.26 It is recommended that the Department of Health, Social Services and Public Safety establish a regional framework for sustained health improvements of the learning disabled population. **(Recommendation 37)** The regional framework should include:

- clear statements on the rights of people with a learning disability to have equality of access to health care under recent legislation and Government policy directives

- specific targets in relation to registration of people with a learning disability with general practices and other relevant family practitioners e.g. dentists

- expectations of health checks and health screening for people with a learning disability with particular reference to key areas that have particular risks e.g. cervical/breast screening, thyroid function tests for people with Down's Syndrome

- specific health promotion initiatives and interventions that focus on improving the health status of people with a learning disability in key areas such as nutrition, obesity, exercise and dental health

- requirements in relation to production of Health Action Plans

- requirements for health promotion initiatives to take account of the particular difficulties experienced by people with a learning disability in accessing information.

7.27 It will be necessary for each Board to review existing Health Improvement Plans for people with a learning disability to ensure that they translate the regional framework at a local level.

7.28 In order to redress the lack of attention given to the particular health issues in policy documents it is recommended that all generic health strategies make specific reference to the needs of and impact on people with a learning disability alongside other minority groups. **(Recommendation 38)**

7.29 In order to support the major practice, organisational and cultural changes required it is recommended that the new role of Health Facilitator be created. The primary role and function of Health Facilitators would be to drive and champion the implementation of the regional framework, support work to achieve the local targets and establish Health Action Planning processes for priority groupings within the population of people with a learning disability. **(Recommendation 39)**

7.30 The Health Facilitator's role would embrace both physical and mental health needs and ensure that people with a learning disability gain full access to the healthcare they need for both primary care and acute hospital services.

7.31 In order to ensure that the specific individual health needs of people with a learning disability are identified and addressed it is proposed that arrangements be set in place to ensure that all are offered a personal Health Action Plan. Health Action Plans detail the actions that are required to maintain and improve the health of people with a learning disability. They encompass a personal plan that outlines the help needed to enable a person with a learning disability to stay healthy, responsibility for which will rest with a named Health Facilitator working in partnership with primary health care staff. Health Action Plans involve people with a learning disability and their family carers in effective multi-agency and multi-disciplinary care planning prepared with and for the individual concerned. The Health Action Plan where possible should form part of a Person Centred Plan. In order to reduce the inconsistencies that can result from local initiatives it is recommended that the broad format for the Health Action Plans be agreed at a regional level. **(Recommendation 40)**

7.32 Health Action Plans should include details of the need for health interventions, oral health, fitness and mobility, emotional needs and records of screening tests. They should also identify clearly who is responsible for taking action.

7.33 Further action is required to raise awareness with primary care services and acute general hospitals of the health issues faced by people with a learning disability. In order to clarify arrangements and ensure that roles and responsibilities are clearly set out between mainstream and specialist learning disability services it is recommended that each general practice and acute general hospital develop clear arrangements to facilitate equality of access for people with a learning disability. **(Recommendation 41)**

7.34 As noted earlier identification of people with a learning disability at primary care level is problematic. Without such identification targeted efforts to improve involvement in health screening and planning for provision is not possible. It is therefore recommended that improvements be made in how people with a learning disability are identified within GP practices (e.g. use of standardised diagnostic codes throughout Northern Ireland). This would have a number of benefits including:

- raising awareness of poor health status and consequent need for practices to focus attention on them
- identification of specific physical and mental health issues that might be targeted locally
- provision of a basis for target setting, monitoring and evaluation. **(Recommendation 42)**

7.35 It is recognised that GPs and other practice staff may require support from specialist learning disability professionals to assist them in providing sensitive and appropriate services. There is a need for Community Learning Disability Teams to more closely align themselves with primary care colleagues. We propose that this be achieved by the development of having a named professional from the Community Learning Disability Teams linked to each GP practice. The link person may be able to resolve some of the common problems experienced by individual people with a learning disability in using primary care services including long waiting times, medication management, communication difficulties. The link person could have a role in:

- practice training sessions in health centres to improve knowledge of learning disability and physical/mental illness
- developing effective partnership work between primary care and learning disability services
- assisting in health promotion initiatives provided for people with a learning disability. **(Recommendation 43)**

7.36 An essential component of supporting optimum physical health is adequate management of associated physical disabilities. To meet the increasing quantity and complexity of needs high specification equipment must be available. The range of wheelchairs and aids available through the Regional Disablement Service should be appropriate to individual need and the budgets will need to be reviewed to reflect the anticipated increase in demand. **(Recommendation 44)**

7.37 Objective 7 Recommendations

Recommendation 37	The Department of Health, Social Services and Public Safety should produce a Regional Framework for Health Improvement of people with a learning disability providing clear direction including targets and timescales. Each HSS Board should review their Health Improvement Plans to ensure that they translate the regional framework at a local level to support improved health outcomes for children, men and women with a learning disability.
Recommendation 38	All generic health strategies, published at Department, Board and Trust level, should make specific reference to the needs of and impact upon people with a learning disability.
Recommendation 39	By December 2009 resources should be made available from within primary care to appoint within primary care a Health Facilitator for each 110- 120,000 population.

Recommendation 40	By December 2008 a Health Action Plan will be developed, as a part of the Person Centred Planning process, which is to be set in place for all those with a learning disability in contact with health and social services agencies.
Recommendation 41	With immediate effect each general practice facility and acute general hospital within Northern Ireland should have clear and formalised arrangements in place to facilitate equity of access to services for people with a learning disability.
Recommendation 42	Each general practice should establish robust medical records and health data about people with a learning disability on their practice register.
Recommendation 43	With immediate effect each general practice should have an identified link person within their local Community Learning Disability Team with whom they work collaboratively to facilitate better access for people with learning disability within primary care settings.
Recommendation 44	Equipment and wheelchair provision budgets should be increased to meet significant additional demand. This will require an increase of the proportion available to people with a learning disability.

MENTAL HEALTH AND CHALLENGING BEHAVIOURS

Chapter 8

> *Mental Health is the emotional and spiritual resilience, which enables us to enjoy life and survive pain, disappointment and sadness. It is a positive sense of well being and an underlying belief in our own worth and others' dignity and worth* HEA 1998 cited in Promoting Mental Health DHSSPS (2003) (122)

8.1 Promotion of mental health is of particular importance for people with a learning disability. Mental health problems are much more frequent among people with a learning disability. The presence of a mental health problem combined with a learning disability makes it even more difficult to cope independently and to make balanced decisions about life and care. In this chapter we will focus on the mental health needs of people with a learning disability and the action required to address them in order to fully achieve Objective 7.

Objective 7 To secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability.

Issues and Concerns

8.2 People with a learning disability can experience the same range of mental heath problems as the rest of the population and there is evidence that they are more prevalent amongst this group. (123, 124)

8.3 Reported prevalence rates vary widely, for example, schizophrenia is three times more common than in the general population. (125)

8.4 There are difficulties in recognising that a person with a learning disability has a specific mental illness and underreporting of mental health problems can occur. (126)

8.5 Within Northern Ireland there is expertise in assessing and treating mental illness in people with a learning disability. This is best evidenced where a number of professionals can work in an inter-disciplinary way. This presently occurs in the three specialist hospitals. There has been limited development of this comprehensive approach in community settings. Access by people with a learning disability to mainstream mental health services is extremely limited. An unhelpful barrier based on IQ currently determines an individual's access to services.

8.6 Many community residential facilities in Northern Ireland have difficulty in providing the specialist support required by people with complex mental illness. They rely on the expertise of outside professionals and admissions to specialist hospitals are higher from these settings than from people living with family carers. (46, 47)

8.7 Health and social services are only in the early stages of developing specific community based services within learning disability services to support people who develop major mental health problems, although some professionals have developed a high degree of specialism while addressing the needs of individuals with whom they work. (127)

8.8 Improved collaborative planning or joint work between specialist hospitals and community based services is a priority.

Challenging Behaviours

> *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 (128)**

8.9 Challenging behaviours may be associated with a mental health problem. They may also be used by an individual:

- to indicate pain or distress
- as a means of communication
- to avoid stressful situations
- as learned behaviours triggered by specific contexts.

8.10 Challenging behaviours can present major difficulties within services and potentially are a significant obstacle to securing the inclusion of individuals in community based opportunities. It is difficult to be certain about the number of people with a learning disability who display severe challenging behaviours largely because of different definitions that have been used. However, research conducted in Northern Ireland indicates that it is a major issue in both community and hospital services.

- Behavioural management was reported as being the third most frequently reported role of community nurses for people with a learning disability. (129)
- Another study of caseloads of all community nurses for people with a learning disability in Northern Ireland found that 28 % of people they work with were reported to have challenging behaviours. (130)
- 70% of people admitted to Longstone hospital over an 18-month period were noted to have challenging behaviour. (127)
- In a study of 154 people admitted to Muckamore Abbey hospital the most common reason for admission was that of a wide range of challenging behaviours (69%). (131)

8.11 The consequences of challenging behaviours can be serious in terms of impact both on the individual involved and on others including:

- people who display challenging behaviours may suffer severe harm due to self-inflicted behaviours

- people with challenging behaviours are more likely to be socially rejected and excluded. This is particularly the case for people with communication difficulties for whom social integration is further reduced. (132)
- parents of children with a learning disability and challenging behaviours have high levels of personal stress and increased social isolation (133)
- sleep disturbance has been reported in 88% of children with challenging behaviour (134)
- staff in services in Northern Ireland have cited issues related to challenging behaviour as a key unmet training need and have highlighted their disquiet at the lack of clear guidance on appropriate methods of working with people whose behaviour is challenging (135, 136)
- the individual may come into contact with the police and criminal justice system.

8.12 There is expertise in the assessment and management of challenging behaviours within hospitals and in community teams. Strategies that have proven successful in addressing challenging behaviours include:

- Applied Behavioural Analysis
- manipulation of the living environment
- education for carers and families.

Action Required

8.13 In addition to the action detailed in Chapter 7 with regard to health promotion, health facilitation and primary care services, we believe that a new model based on community provision is required to address the needs of men and women with a learning disability who have mental health problems and/or display challenging behaviours.

8.14 Other Expert Working Committees of the Review of Mental Health and Learning Disability (NI) will address:

- **forensic issues** especially the interface between mainstream forensic mental health services and specialist learning disability provision in the areas of prevention, continuity of care as well as in specialist assessment and treatment. Individuals with a learning disability can be particularly vulnerable when in contact with the criminal justice system. This can occur in police stations, when attending court, in prison and young offenders centres and on probation. There must be a full range of inpatient care, including high, medium and low security services. In addition there is a need for Community Forensic Services to support the full range of people with a learning disability in the community, including those who have been discharged from hospital or released from prison. Detailed consideration of the needs of people who require the support of specialist forensic services will be included in a separate report.
- **child and adolescent mental health.** We anticipate that mainstream services will take the lead role for those with a mild and moderate learning disability with joint working becoming more common for those with a more severe learning disability.
- **alcohol and substance misuse.** Amongst people with a learning disability who have problems with substance misuse or alcohol problems, most will have a mild learning disability. The combined problems of substance misuse with a learning disability, possibly with an additional

mental health problem, greatly increases concerns regarding vulnerability and the capacity to make informed life choices. Mainstream addiction services require an individual to have a high level of motivation and a desire for change to benefit from treatment. People with a learning disability need particular support to assist them to take part in such treatment when their capacity to make informed life choices is impaired. Specific recommendations regarding development of this aspect of the service are contained in the report from the Alcohol and Substance Misuse Committee.

- **mental health promotion.** It is clear that both children and adults with a learning disability are exceptionally vulnerable to mental health problems and as a result of this vulnerability, there has been an impetus towards detecting, assessing and treating mental health problems in this population. Such an impetus, whilst very necessary, is reactive by its nature, and a key message is that little attention has been given to the development of robust proactive and preventative strategies that build resilience and protect people with a learning disability from the development of mental health problems. Emphasis should be given within all relevant sectors to building positive mental health from childhood onwards. Schools and colleges in particular have immense potential to contribute to and enhance young people's emotional development.

- **mental health issues in old age and dementia.** Service developments and provision that have been found to be helpful with the general population need to be applied within learning disability services. We anticipate joint working arrangements to be common practice.

- **legal issues.** Issues such as guardianship, capacity, compulsory admission for assessment and treatment, the Mental Health Review Tribunal, advocacy, legal representation, indeed what type of legislation should replace the existing Mental Health Order (NI) 1986 are all matters which clearly affect people with a learning disability and will be addressed by the Legal Issues Committee.

8.15 The Expert Working Committee on Adult Mental Health has incorporated proposals for addressing the mental health needs of people with a mild learning disability in mainstream mental health services which supports the model of provision which follows.

8.16 Simply having a learning disability has been enough to exclude people from accessing services. We suggest that a collaborative system of care between mental health and learning disability services will best meet the needs of this most vulnerable group. Historically in Northern Ireland more individuals with mild/borderline IQ levels did access mainstream services. However over recent years this practice has been diminishing.

8.17 A significant proportion of adult admissions to specialist learning disability hospitals are people with a mild/moderate learning disability. Many of these admissions could be prevented if appropriate community supports were in place. People with a mild learning disability should be able to access mainstream mental health services where these services are appropriate to meet their needs. Mainstream services include child and adolescent mental health services, mental health services for adults of working age, mental health services for older people, forensic mental health services, substance misuse services, brain injury services etc. The benefits of this approach include facilitating access to a wider range of expertise and increased access to local services. It is recognised that achieving this shift may initially give rise to clinical concerns about the quality of the experience for the individual. However, these concerns will be reduced if adequate energies are directed towards increasing the collaboration between learning disability services and mainstream services and to developing protocols whereby the skills of learning disability specialists are appropriately shared across programmes. **(Recommendation 45)** In order to achieve this it would be necessary to greatly strengthen links between learning disability services and mainstream mental health services. **(Recommendation 46)**

8.18 In order to address the low level of community provision and the consequent over dependence on hospital based interventions it is proposed that community based assessment and treatment services be further and more robustly developed. These should be built on existing professional expertise. Training that involves the sharing of skill and knowledge across the range of professionals can enhance expertise.

8.19 A model for community service would include community assessment and treatment teams who would be competent in addressing mental health problems and challenging behaviours. Crucially the teams should provide an outreach service to homes and services in the community and be available outside of normal office hours. Such a community service would include a range of accommodation options providing a variety of supports. It is proposed that such services be developed incrementally in order to enable an appropriate remodelling of current hospital provision and the development of appropriately piloted protocols, eligibility criteria and operational systems. The regulatory status of this provision will also need to be clarified, as it will be a new service model that does not readily fit with current regulation categories.

8.20 Outcomes and benefits of this model are:

- a local, safe, secure alternative to acute hospital admission
- easement on demand for hospital admission
- reducing length of stay of hospital admission
- continuity of normal lifestyle pattern through continued community integration
- maintenance of family and/or current placement links
- reducing numbers of hospital re-admissions
- facilitating time out of home without using a hospital place
- fewer obstacles to communication because of closer geographical base
- review assessment and alteration of medication through local psychiatry input
- less traumatic experience for the individual
- more appropriate targeting to meet specific needs
- more person centred approach
- greater continuity/stronger links to local learning disability supports
- better use of acute scarce resource
- local services encourage care and resolution to the individual's difficulties
- effective and co-ordinated liaison and integration with other local services. **(Recommendation 47)**

8.21 As a consequence of the development of community based assessment and treatment services, admission to specialist hospitals solely for people with a learning disability will become increasingly less frequent. DHSSPS should commit to reviewing and evaluating the developing community services and the need for continuing specialist hospital provision. Ultimately it is hoped that there may not be a need for specialist hospitals for assessment and treatment solely of those with a learning disability.

8.22 In order to enable community provision to develop there is a need for clarity about the shift in resources and the additional funding that will be required. This should be agreed at a regional level in order to avoid perpetuation of service inequities and to address the complex issues involved in commissioning this level of specialist provision. This should take account of the training requirements for the recognition of mental health and challenging behaviour problems across the whole range of people providing care and support. **(Recommendation 48)**

8.23 A small number of people with a learning disability have severe challenging behaviour or mental illness that is liable to relapse. Staff and carers must be alert to warning signs of a recurrence and share information about such signs. To encourage better liaison and clarity of roles and responsibilities between specialist and community services in relation to such people, Health and Social Services Trusts should ensure that protocols are agreed for proactive approaches to intervene in a systematic way should there be warning signs of recurrence. **(Recommendation 49)**

8.24 There is a significant level of concern raised by staff about the lack of guidance on the appropriate management of challenging behaviours and the complex legal, human rights and practical issues involved. It is recommended that a regional approach be adopted to developing clear guidance in this area for all learning disability services in Northern Ireland. Similar initiatives in England have assisted in providing a framework in which both people with a learning disability and their carers can be supported and the required training strategies developed. **(Recommendation 50)**

8.25 Objective 7 Recommendations

Recommendation 45	As a matter of urgency the Department of Health, Social Services and Public Safety should consult with all 4 Health and Social Services Boards about their present and future plans for specialist assessment and treatment services for men and women with a severe learning disability with a view to greater sharing of existing and planned resources and the development of new forms of community based services.
Recommendation 46	By the end of the Review period people with high levels of adaptive functioning/mild learning disability who require therapeutic intervention as a result of mental health problems should be able to access mainstream mental health services. Support from dedicated learning disability services should be available if required.
Recommendation 47	Community based assessment and treatment services should be developed on an incremental basis to provide assessment and treatment of men and women with a learning disability who have specific mental health needs and/or challenging behaviours. The community based assessment and treatment services will encompass behaviour support expertise that will provide outreach to individuals, families and community services and short-term intensive treatment to those within a residential facility which may be approved to treat people under mental health legislation.
Recommendation 48	As a consequence of the other mechanisms being recommended the Department of Health, Social Services and Public Safety should establish a regional plan that sets targets for the reallocation of existing resources and the securing of additional resources to enable the community services to be established.
Recommendation 49	Some people with a learning disability are at increased risk of recurrent severe challenging behaviours and/or mental illness. Health and Social Services Trusts should ensure that protocols are agreed so that a proactive approach can be taken to systematic intervention should there be signs of recurrence.

Recommendation 50 By December 2006 the Department of Health, Social Services and Public Safety should produce in partnership with service providers regional guidelines on the management of challenging behaviours within services.

GROWING OLDER

Chapter 9

One of the great social achievements of the 20th century has been increased longevity of people with learning disabilities due to advances in medical care and social support. (137)

9.1 The life expectancy and number of older people is increasing across most developed countries. Most people with a learning disability who survive beyond 30 years will have average life expectancy and experience normal ageing processes. Many will experience a long and healthy old age. Growing older is also likely to include a number of additional challenges for people with a learning disability owing to the impact of their disability. The Equal Lives Review found limited evidence of strategic planning, specific policy or changing practices that will meet the emerging needs associated with increased numbers and needs of older men and women with a learning disability or their family carers in Northern Ireland.

Objective 8 To ensure that men and women with a learning disability are supported to age well in their neighbourhoods.

Issues and Concerns

Difficulty in Definition

9.2 Old age is a relative concept, the definition of which is affected by social, psychological and biological factors. Therefore, being old might be defined by social benchmarks such as retirement age, physical signs of ageing, or the degree to which one feels old.

9.3 Men and women who have a learning disability may experience each of these quite differently. The degree to which many men and women with a learning disability have been excluded from the social opportunities and life chances available to others means that society's benchmarks may be applied less satisfactorily, as typified by the question posed to us by a man with a learning disability at a meeting, *Am I ever going to be allowed to retire from my day centre?* The physical signs of ageing may affect some people with a learning disability at an earlier age. (50) There is limited evidence on how well men and women with a learning disability cope psychologically with ageing. It could be that due to cognitive limitations some people find difficulty understanding the ageing process. This may be worsened by the fact that many individuals with a learning disability are prevented from experiencing normal life events e.g. they may be hindered in the acceptance of mortality, as they are frequently not exposed to rituals such as funerals in an attempt to protect them from unpleasant events. (49)

9.4 Owing to these factors and the potential additional supports that may be required, it has been proposed that planning to meet the ageing needs of men and women with a learning disability should begin at an earlier stage and no later than 50 years.

Impact of Ageing

9.5 As noted there may be significant differences in the impact of ageing for men and women with a learning disability as compared with other people in Northern Ireland.

- 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 deterioration in function in virtually all aspects of life, a disintegration of the affected person's personality and eventually death. Research evidence indicates that people with Down's Syndrome show neurological changes resulting from Alzheimer's type dementia at a much younger age than others, and in addition virtually all people with Down's Syndrome who live long enough will develop this type of dementia. (138)

Table 3: Percentage of people with Down's Syndrome affected with Alzheimer's Disease (139)

Age in years	Rate %
30-39	0-10%
40-49	10-30%
50-59	20-55%
60-69	30-75%

- Men and women with a learning disability may also develop what are known as syndrome-specific conditions including congenital heart defects/visual and hearing disorders (Down's), musculo - skeletal problems (Fragile-X) and obesity related diabetes (Prader-Willi). (138, 140-144)

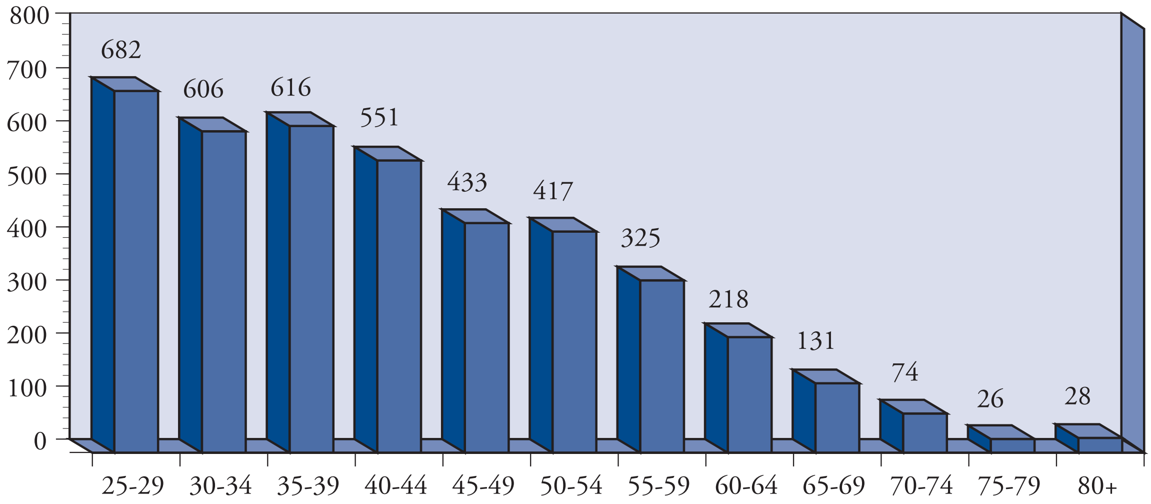
9.6 Between 20-40% of older men and women with a learning disability are liable to have a mental health problem. (145)

Numbers

9.7 There is clear evidence of the increased numbers of older men and women with a learning disability in Northern Ireland.

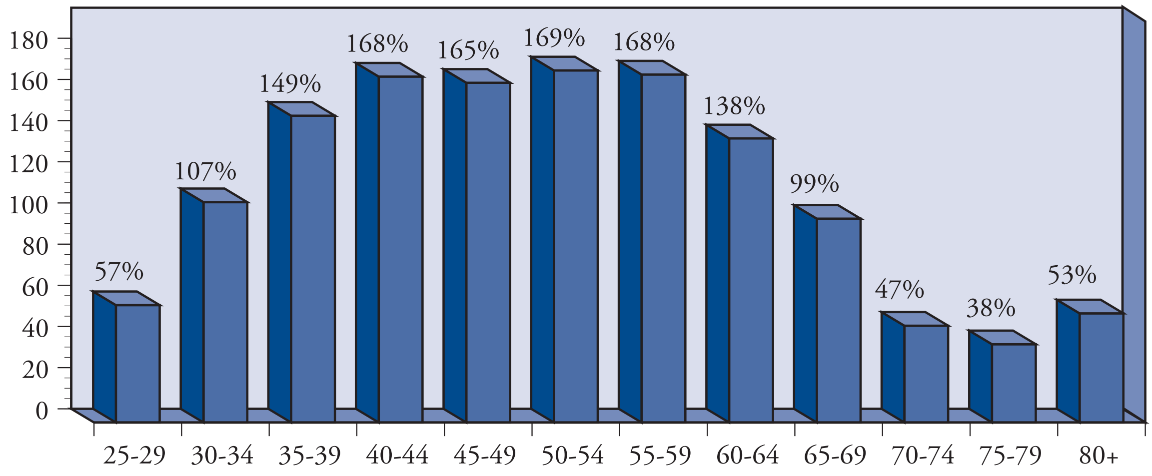
- The prevalence study of people with a learning disability in Northern Ireland (15) identified that out of 4,107 people with a learning disability living in ordinary homes 477 (12%) are aged over 60 years of age (Figure 7). If we applied the definition of old age as starting at 50, then 1219 (30%) people could be considered to fall within the older adult population.

Figure 7: The number of people living in community settings (i.e. with family carers; own accommodation) in 5-year age bands. (N=4107) (15)



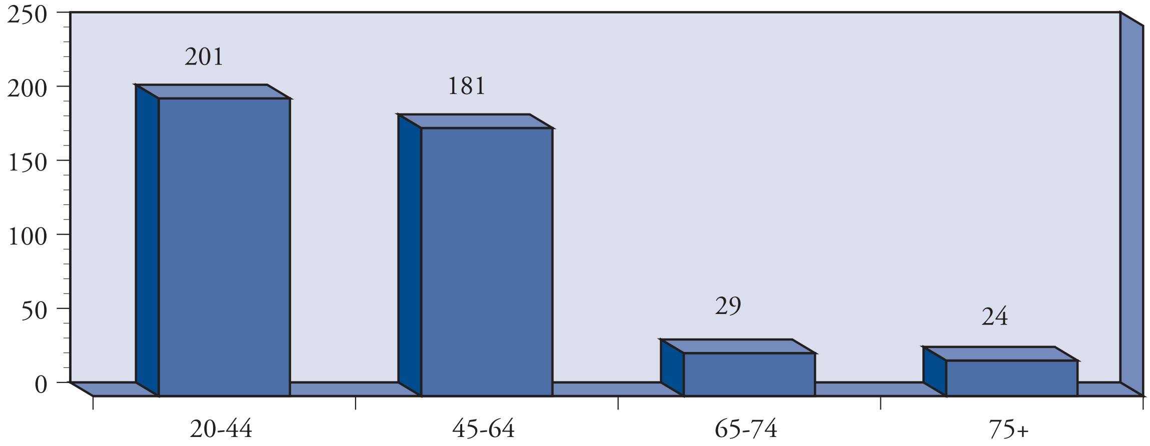
- This study also identified the number of people with a learning disability living in residential or supported living. These figures show that of 1,358 people in supported/residential living, 375 (28%) were over 60 years of age and 712 (52%) were aged over 50. (Figure 8)

Figure 8: The number of people living in residential and supported living settings in 5-year age bands (N=1358) (15)



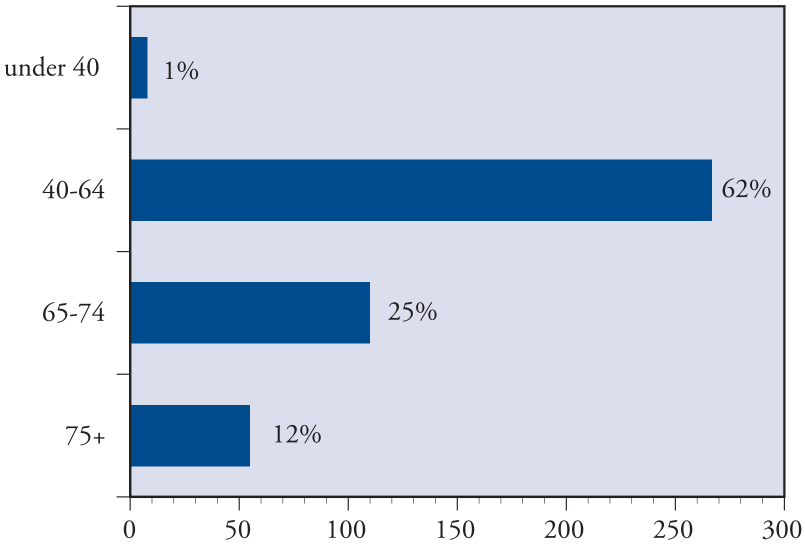
- Of the 435 men and women with a learning disability who had been in a hospital for more than one year, 53 (12%) were aged 65 years and over and over half of the hospital residents (234, 54%) were aged 45 years and older. (Figure 9)

Figure 9: The number of in-patients in hospitals greater than 366 days in age bands (N=435) (15)



- In another study in Northern Ireland that investigated future housing needs in one Board area, 37% of family carers were over 65 years old. The report author projects this to the other data presented and estimates that nearly 500 men and women with a learning disability live with a carer aged over 75 years, and a further 1,000 people live with a carer aged over 65 years.

Figure 10: The number and percentage of primary carers by age bands looking after people with a learning disability aged 25 years and over in EHSSB area (N=436) (99)



Family Carers

> *Over the last few months I have been to three funerals of adults with a learning disability. Each time I hugged the mother and told her now you can let go. Parents worry so much what will happen to their children after they die that they pray that their son or daughter dies first so they will not be left to fend for themselves.* (2)

9.8 Family members continue to provide the bulk of caring as men and women with a learning disability grow older. For many this can be a positive experience and a preferred choice over other options because of a number of 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 fulfilling the caring role. (146, 147)

9.9 However, there are a range of issues relating to the role of family carers as they and their relative get older including:

- older family carers are under greater physical and mental pressures because of their age and the frailty this often brings; and as they age, they become increasingly anxious about the future
- because of the duration of the caring relationship, which is often life-long, they are likely to have a particularly intense, interdependent relationship with the person they are supporting
- they are more likely to be caring alone
- they have smaller support networks as parents, partners and friends age and die
- they have a very different experience of the service sector from new generations of carers. They were often advised to forget or reject their child, encouraged to have very limited expectations of his or her life expectancy or abilities and usually had to fight very hard for any support from the statutory sector.
- older family carers are often very reluctant to seek help. Reasons for this include past negative experiences of the paid service sector, and a fear that by seeking help they are admitting their own diminishing capacity and that they will lose control. (146)

9.10 Similar issues have been described in the limited research in Northern Ireland on the experiences of older people with a learning disability or their carers e.g. one study in a Health and Social Services Trust found that:

- deterioration in mobility of their ageing relative was the most common problem reported by family carers 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 6 months to one year. (147)

9.11 Despite the fact that family carers are entitled to a separate assessment of their needs we found that there was a very limited awareness or uptake of this amongst family carers in Northern Ireland. (2)

Futures Planning

9.12 During the consultation for the Equal Lives Review family carers frequently raised their concerns about the future and a wish for workers to support them to make plans for when they may no longer be able to meet the care needs. However, they noted how difficult this was and that on occasions an apparent refusal to look towards the future was a reflection of the pain involved in contemplating their own mortality and the consequences for their son or daughter. (2) Carers were particularly concerned that futures planning should address issues of capacity and consent, to ensure that this responsibility was appropriately placed in the absence of the main carer. There are few precedents for older people with a learning disability remaining in the family home in the absence of the main carer. This offers considerable scope for extending the range of housing options available to older men and women with a learning disability.

9.13 There has been a serious dearth of service planning to meet the future needs of men and women with a learning disability as they age. This is reflected in the very limited local research, absence of a departmental steer on expectations of services to develop appropriate responses, confusion about the interlinking roles of learning disability, older people and dementia services and an apparent failure to recognise the potential pressures arising from the increased numbers and needs on future service provision. One result has been that older men and women with a learning disability are being moved from their accommodation, and often their familiar day supports, at extremely vulnerable periods in their lives.

Ageing Well

9.14 In contrast with developments for older people generally there has been little emphasis on health and well being for people with a learning disability. Ageing well has not been actively encouraged or supported by services to date. The consequences of this are now becoming evident in our population of older people with a learning disability.

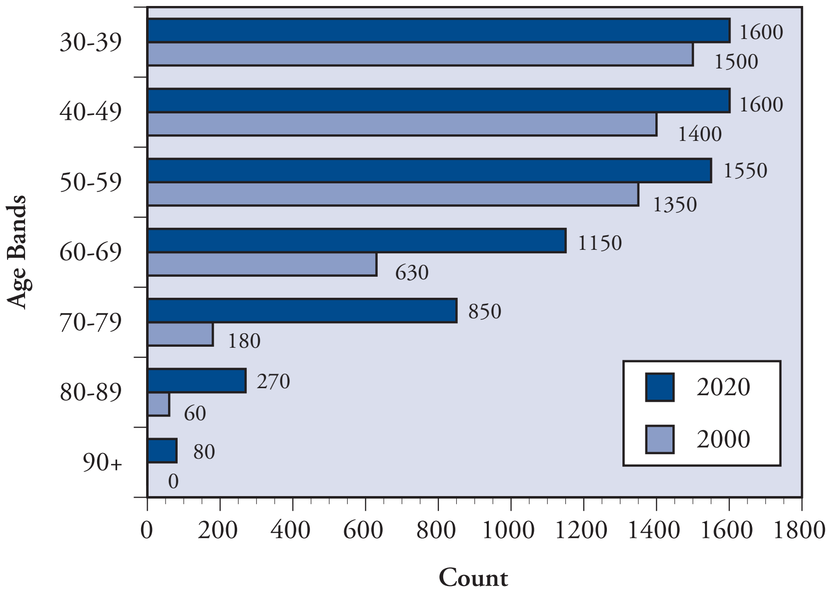
- Older men and women with a learning disability have few opportunities to take part in leisure pursuits. (148) This is due to the health problems they face, perceptions of them as a lower social status group, exclusion rather than inclusion within their community and lack of support to access leisure activities. (149)

- In line with the general population, issues around diet and exercise are coming to the fore and are generally exacerbated for people with a learning disability due to many factors, not least their poor access to primary care services. (150, 151, 152)

Action Required

9.15 Over the next 15 years using predictions for the wider population, we estimate that the number of men and women with a learning disability in contact with health and social services who are aged over 50 years will rise from around 2,200 in 2000 to 3,900 as Figure 11 shows; a predicted increase of 81%. The figure of 3,900 represents around 0.58% of the predicted population of people aged over 50 in 2020 (672,000) and 1.23% of the predicted population aged 65 years and over (319,000).

Figure 11: Projected increase in the number of people with a learning disability from 2000 to 2020.



9.16 In order to remedy the serious lack of strategic planning to address the particular issues associated with ageing there is an urgent need for focused planning and reconfiguration of service delivery in this area.

9.17 As the ageing process for some men and women with a learning disability may begin much earlier, planning for them should begin much earlier. Planning for those people aged 50+ should be prioritised immediately, and should be developed in conjunction with people with a learning disability. As PCP is progressed with all people, planning for the future will naturally happen from an earlier age. We suggest that it includes those aged 50 and upward, which would mean that:

- monitoring would allow early identification of potential problems and thus improved planning to meet this growing need
- potential crisis management could be avoided especially following the death of a sole carer
- service user and family education and preparation for growing old could be planned for earlier and therefore be more effective.

9.18 Redefining ageing in this manner would necessitate revised arrangements for the allocation of resources to meet the needs of this group. In particular the interface between funding for elderly services and that for learning disability services would need to be reviewed and more flexible connections between both programmes facilitated. (Recommendation 51)

9.19 An ageing in place culture should be facilitated by support services if, through PCP, men and women with a learning disability and family carers reveal that this is their preferred option. Research indicates that this is most likely to be the case and is certainly the most cost-beneficial option for HPSS services. This raises fundamental questions about the most appropriate service model(s) to meet the needs of both family carers and older people with a learning disability.

> *We are not sure whether we should be valuing our elderly clients by regarding them as people with unique needs or valuing them by treating them no differently from anyone else.* **Moss** (152)

9.20 There are potentially a number of models that might be developed including:

- developing expertise within learning disability services to enable them to meet the needs associated with ageing
- ensuring that older men and women with a learning disability can access supports from services for older people and possibly before 65 years of age
- developing clear linkages between specialist learning disability services and older people's services to ensure that skills are shared between both groups but facilitating greater choice by men and women with a learning disability so that they can age in place if desired.

9.21 Applying the Equal Lives Values and in particular the requirement to individualise support planning, it is evident that within future provision there may be a need for not one, but several models. Clearly this would require greater cross-programme and multi-disciplinary co-operation. There will also be a need for a more flexible approach to resource allocation to meet the joint needs of both the individual and their elderly family carer. The interdependence of both must be recognised.

9.22 Given the absence of coherent work in Northern Ireland to address these issues we believe that a regional approach should be adopted to develop clarity about the strategic direction to be taken and the changes to organisational structures and systems that should ensue. This work should be led by the Department of Health, Social Services and Public Safety and involve the development of a regional network wherein knowledge and expertise about ageing issues might be further researched, shared and developed. The outcome should be a regional framework that addresses at least the following:

- values and principles derived from the Equal Lives values as they apply to the ageing population of people with a learning disability
- information audit of need
- creation of a policy framework
- development of local partnerships between learning disability services and the elderly programme of care
- human resource implications in both of the above sectors
- strategy for optimising health
- involving older people with a learning disability in decision-making
- promoting positive lifestyles for older men and women with a learning disability through voluntary and community organisations
- forward planning[8]. **(Recommendation 52)**

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[8] Adapted from the checklist for action in Preparing for a Positive Future (153)

9.23 There is a need for a complementary process to be undertaken to address the issues for men and women with a learning disability who develop dementia including those who are younger. These issues are currently under consideration by the Expert Working Committee on Dementia and Mental Health Issues in Older People of the overall Review. We recommend that the framework that is developed ensure that men and women with a learning disability who develop dementia should be enabled to access support and expertise from mainstream dementia services in their locality. This will require close cooperation between learning disability specialists and those who have expertise in dementia. **(Recommendation 53)**

9.24 Objective 8	**Recommendations**
Recommendation 51	The Department of Health, Social Services and Public Safety should review funding allocations to ensure that the projected increase in numbers of older people with a learning disability is reflected in the allocations to the learning disability programme. This shift will take cognisance of the fact that people with a learning disability may experience the effects of ageing at an earlier age.
Recommendation 52	The Department of Health, Social Services and Public Safety and Health and Social Services Boards should produce a strategic plan to address current deficiencies in services and future service provision for older people with a learning disability and their families.
Recommendation 53	Arrangements should be developed to enable people with a learning disability who have dementia to access support and expertise from mainstream dementia services. This will include mechanisms to provide a skills boost between dementia services and dedicated learning disability services.

ENSURING PERSONAL OUTCOMES

Chapter 10

> *We hope that the Review will make sure that there are more advocacy groups and more chances for people to speak out and be listened to. We do not think this happens enough and that is why things go wrong.* (1)

10.1 The Equal Lives Review has concluded that progress needs to be accelerated on establishing a new service model, which draws a line under outdated notions of grouping people with a learning disability together and their segregation in services where they are required to lead separate lives from their neighbours. The model of the future needs to be based on integration, where people participate fully in the lives of their communities and are supported to individually access the full range of opportunities that are open to everyone else. This will involve:

- developing responses that are person centred and individually tailored
- ensuring that people have greater choice and more control over their lives
- services becoming more focused on the achievement of personal outcomes, i.e., the outcomes that the individuals themselves think are important
- increased flexibility in how resources are used
- balancing reasonable risk taking and individuals having greater control over their lives with an agency's accountability for health and safety concerns and protection from abuse.

10.2 In this chapter we will outline the issues that support or impede this direction of travel and the specific actions that are required to achieve it.

Objective 9 To enable people with a learning disability to have as much control as possible over their lives through developing person centred approaches in all services and ensuring wider access to advocacy and Direct Payments.

Issues and Concerns

Person Centred Approaches

10.3 Throughout the Equal Lives Review process it was evident that many services in Northern Ireland are seeking to develop a greater focus on meeting individual needs and aspirations through person centred approaches to planning and support.

10.4 However, PCP appears to have been the result of determination on the part of individuals or groups within services to transform working methods rather than a consequence of a shift in strategic direction within organisations. Therefore, as in other areas of practice, the likelihood of being offered the opportunity to participate in a PCP process depends more on where you live rather than on the degree to which you might benefit. (1)

10.5 There is some confusion about the terms in use, which we seek to clarify here.

PERSON CENTRED APPROACHES

…ways of commissioning, planning, and organising services that are based on listening actively to what people want and tailoring services to individual needs rather than fitting people into available services.

PERSON CENTRED PLANNING (PCP)

…a process for continual listening and learning focusing on what is important to someone now and in the future and acting on this in alliance with their family and friends. (154)

PERSONAL OUTCOMES

…the effects of an intervention that focus on the issues that matter most to people in their lives and checking to ensure that they are being met.

10.6 Developing a person centred approach within existing service agencies will require cultural and organisational changes and fundamental shifts in the ways in which decisions are taken and implemented.

10.7 Throughout the Equal Lives Review people expressed considerable support for PCP to be made available to all people with a learning disability. This support was voiced at presentations to the Learning Disability Committee, at meetings with the Equal Lives Group and carers and by each of the 6 Task Groups. Future energies will need to focus on ensuring that where person centred plans are developed, sufficient attention is given to their implementation to ensure that they result in better outcomes for the individual.

Direct Payments

10.8 The Carers and Direct Payments Act (NI) 2002 makes provision for people to have increased control over the services they receive and for carers to have their needs recognised formally. The Act:

- requires Health and Social Services Trusts to inform carers of their right to an assessment
- gives carers a statutory right to assessment of his/her ability to provide and continue to provide care for the person cared for
- places a duty on Trusts to supply services that meet the personal needs of carers as well as the person they care for
- enables carers to purchase, through a Direct Payment, the services they require to meet their own assessed needs.

10.9 There was a low level of awareness about these provisions amongst the carers who attended the Equal Lives Review meetings. Concern was also expressed about the length of time taken to complete these procedures and the level of support that was offered as a result. (2)

10.10 The Community Care Direct Payments Act (1996) made it possible for disabled people, including those with a learning disability, to have a Direct Payment from Health and Social Services 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. There has to date been a very low uptake of Direct Payments by people with a learning disability in particular but also among others with a disability . At March 2004, out of 107 people in receipt of Direct Payments in Northern Ireland, 12 had a learning disability. (155) The Belfast Centre for Independent Living has established an advice and support service in Direct Payments which to date has had limited requests from people with a learning disability or their family carers.

Advocacy and Information

10.11 Current Government policy stresses the importance of people being able to have a say about how services are run and for services to be more user-led. Yet many people with a learning disability find it hard to make their voices heard. Advocacy can help people let others know what is important to them and have influence over decisions, which affect them.

10.12 Compared with England, Scotland and Wales, the range and volume of advocacy services for people with a learning disability in Northern Ireland is low. There are examples of good practice throughout Northern Ireland, but these are sporadic and often groups are relying on unpredictable funding and volunteer support to keep them going. Very few people that we met during the Equal

Lives Review meetings had access to an independent advocate or to opportunities for support in self-advocacy. (1) There is no regional forum of people with a learning disability.

10.13 Between 50% and 90% of people with a learning disability have some communication difficulties (depending on the definitions used and the survey population). Four out of 5 people with severe/profound learning disabilities have no effective speech, although they will demonstrate what they want to communicate by other means. (156) This places an onus on agencies to ensure that people with a learning disability are informed about issues that will affect them in a way that takes account of their communication needs. Agencies also need to hear what people say and adapt their processes to ensure that people are listened to.

Quality

10.14 As noted above the benefits of PCP were regularly highlighted to us during the Equal Lives Review. However, we are concerned to ensure that PCP is not viewed as an end in itself. Rather it is the first step in the process of ensuring that people with a learning disability and family carers achieve personal outcomes through their involvement with support services. To us this is the core definition of a quality service.

10.15 Key drivers for measuring and assuring that this happens are the commissioning processes of funders and the monitoring of standards by regulators. There are currently no agreed systems for assessing the quality of life and personal outcomes for people with a learning disability across the full range of services on offer to them. Much current regulation of residential and nursing homes focuses on issues of physical structure and process rather than on measuring the impact on people's lives through determining what the individual regards as important. Growing emphasis on health and safety legislation has created further pressures to institutionalize services in order to meet stringent standards.

10.16 The Government is engaged in a series of initiatives that are designed to improve quality in services. A key element of this is the establishment of the Health and Personal Social Services Regulation and Improvements Authority (HPSSRIA), which will inspect care services against a set of national care standards. This development has the potential to support the increasing emphasis that we feel is needed in all services for people with a learning disability on personal outcomes. However, a number of people who contributed to the Equal Lives Review raised concern that unless the care standards are based around promoting person centeredness in services the opportunity for them to support the inclusion and individualised aspirations of service beneficiaries will be lost. More worryingly, this development will run counter to the values underpinning the Equal Lives Review.

10.17 This emphasis on personal outcomes is equally applicable in specialist assessment and treatment services relating to a person's physical and mental health, or their challenging behaviour. It is imperative that the contribution of these services is closely aligned to the broader PCP for the person.

Research and Information Needs

10.18 In order to raise the quality of supports it is necessary to have a sound evidence base on which to base recommendations for change, development or maintaining existing practices. As part of the Equal Lives Review an audit of learning disability research was commissioned and disseminated on the Review website. This audit highlighted the value of such concrete links between research and policy formulation and practice. It also raised a number of issues that need to be considered in ensuring that the implementation of the Equal Lives Review's recommendations is supported by a coherent research strategy. Further research on the assessment of personal outcomes and the impact of person centred planning should be a key area for research and development during the first 5 years of the implementation of the Equal Lives Review.

10.19 We have highlighted the deficiencies that exist related to information and research on issues relevant to learning disability. The audit of learning disability research undertaken for the Equal Lives Review has identified key research findings that service providers and commissioners need to address along with the significant gaps in our knowledge. The list below is not exhaustive, but is included to highlight the significant gaps that exist in terms of meeting the change agenda detailed in the Equal Lives Review:

- the socio-educational outcomes for children, families and schools when pupils with a learning disability attend mainstream schools compared to special schools
- meeting the personal support needs of family carers at different stages of their son or daughter's life cycle - new born; transition to adulthood; maturity - and as they, as parents, approach old age
- the benefits systems and the impact on poverty in families and people with a learning disability
- tracking young people through different transition routes to understand better the outcomes of various options open to them - college, employment, and day centre attendance
- evaluating ways of increasing the social connectedness of teenagers and adults with a learning disability
- the contribution of productive work - paid and unpaid - in the lives of people with a learning disability
- exploring the obstacles to self-advocacy and how they are best overcome
- ensuring equality of access to healthcare in all its forms for people with a learning disability
- reducing obesity among people with a learning disability
- establishing the outcomes of various accommodation and support options for people with a learning disability, who also have challenging behaviours/mental health problems
- supporting people with a learning disability who have dementia in community settings
- promoting the engagement of volunteer helpers in learning disability services
- evaluating the role of community development agencies in promoting the social inclusion of people with a learning disability.

Action Required

10.20 In order to ensure that people with a learning disability and their family carers have a greater say in decisions that affect them and to support the development of more person centred approaches, there is a need for radical shifts in how organisations operate and opportunities available for participation and influence. We will develop this theme further in Chapter 12.

10.21 The cornerstone of this work will be embedding PCP throughout services and ensuring that all those individuals in contact with health and social services are enabled to have a PCP developed with them if they so choose. This plan will be co-ordinated by the lead worker from the agency that is identified by the person and their support staff as being best placed to do so and the PCP would be held by the individual but shared with their permission with all agencies and personnel involved with the individual.

10.22 At various stages in the Equal Lives Review we have proposed that PCP is particularly important at the point of discovering that a child has a learning disability, in preparing for the transition to adulthood, and in enabling people to plan for the future as they get older. In addition priority should be given to developing a PCP with individuals with complex needs including those who may have particular difficulties in communicating their needs and aspirations as a result of having an Autistic Spectrum Disorder or severe learning disability. Achieving this will require organisations to work collaboratively and to undertake reviews to their current practices especially to enable the shift in attitude and culture that effective PCP requires. **(Recommendation 54)**

10.23 Direct Payments have the potential to be highly effective in giving people control over their lives. Supporting people to purchase the support they need to fit their own unique circumstances should be a key driver towards helping them achieve personal outcomes. Even a modest increase in the uptake of Direct Payments by people with a learning disability and family carers of 10% per annum over the next 15 years would result in around 1,000 beneficiaries (Based on people aged over 20 and children with severe/profound disabilities). There is clearly a need to more widely promote this option and to create more flexible resource allocation to enable it to be taken up by those who wish to do so. However, all these costs could not be met from within existing HPSS budgets as only a small proportion of present funding is spent on variable costs. Thus in England, the Department of Health announced an additional £9million over 3 years to boost Direct Payments for people with a learning disability. A similar initiative is required in Northern Ireland in order to support the uptake of Direct Payments. **(Recommendation 55)**

10.24 In order to ensure that people are supported to have their views heard and acted upon there is a need to address the underdevelopment of independent advocacy services in Northern Ireland. Advocacy can take many forms including group advocacy, self-advocacy and citizen advocacy. In all cases advocacy services should fulfil 3 roles: educational - raising awareness about the strengths, needs and aspirations of people with a learning disability within the community at large; bringing about change to the way that systems work with individuals; and creating collaborative links between people with a learning disability and other groups/organisations in the wider community. The extension in range and volume of advocacy services should be a key priority for planners in the future if more person centred outcomes are to be attained. The development of advocacy services will also facilitate the establishment of a Regional Forum of People with a Learning Disability that we believe is an integral component of implementation arrangements for the Equal Lives Review. **(Recommendation 56)**

10.25 In Chapter 4 we recommended that steps be taken to address the gaps that exist in ensuring that information is available that meets the needs of people with a learning disability and their families. We believe that in addition to this specific measure there is a need to encourage all those who provide services to people with a learning disability to take steps to ensure that they produce information in accessible ways that are tailored to meet the needs of the specific individuals with whom they work. **(Recommendation 57)**

10.26 In order to ensure that the Government's drive to improve quality is meaningful there is a need to develop measures that address the effectiveness of organisations in delivering personal outcomes. This will mean that systems have to be more responsive to the fact that desired outcomes of support are highly individualised and that the focus needs to be on the issues that matter most to the individual who is being supported. If standards are developed that effectively measure personal outcomes in this way, regulators and service commissioners will have a key role to play in promoting person centeredness in services with correspondingly less emphasis on setting standards to be applied uniformly across a diversity of service responses. **(Recommendations 58, 59)**

10.27 It is proposed that the research requirements identified are addressed through the development of an agreed learning disability research strategy, which will encompass the following elements:

- development of links between Northern Ireland researchers and other national and international researchers in learning disability in order to access more research funding
- consideration of the uptake of existing research findings and their use in decision-making
- the participation of stakeholders in deciding on research questions
- the development of researcher-practitioners
- boosting the amount of resources available for research and development within Northern Ireland
- instigating and managing cross-national research projects.

10.28 In conducting the Equal Lives Review we have highlighted difficulties in accessing accurate information on the numbers, needs and services available to people with a learning disability and on the amounts of funding being invested in services for them. In order to accurately evaluate the impact of the implementation of the Equal Lives Review recommendations and to plan more effectively there is a need to establish better systems for tracking people and funding and assessing outcomes. In particular new systems should provide information on services and supports needed by individuals as well as those they are receiving. These records should allow for better integration of information that to date is held separately in education, health, social services or housing systems, taking account of the Data Protection Act. Experiences in England, Scotland and Republic of Ireland would help to inform the development of an appropriate data set. **(Recommendation 60)**

10.29 Objective 9 Recommendations

Recommendation 54 By 1 January 2009 the opportunity to have a PCP should be in place for all persons with a learning disability who are in contact with HPSS agencies. From 2006 priority should be given to:

- developing Family Support Plans based on person centred principles that cross disciplines and agencies
- developing an Early Intervention Plan for children at the point of diagnosis
- ensuring that all young people with a learning disability have an effective Transitions Plan based on PCP principles in place from 14 years of age
- ensuring that all persons living with a sole family carer and/or those aged over 50 years have been offered the opportunity to have a Futures Plan agreed based on PCP principles. In addition a plan for meeting the needs of carers should be prepared. This invitation should be re-issued to family carers and the person they care for on a regular basis and no less than every 3 years.

Recommendation 55 The use of Direct Payments should be widely promoted and additional revenue monies of up to £300,000 per annum over the next 3 years ear-marked by the Department of Health, Social Services and Public Safety for the development of increased uptake of Direct Payments.

Recommendation 56 An independent advocacy service should be in place for each area serving a population of 100,000 - 120,000. A Regional Forum for People with a Learning Disability should be established with representatives drawn from local advocacy services. Both initiatives should be grant-aided through Office of the First Minister and Deputy First Minister (OFMDFM), so that they can cover all services and not just those provided by the Department of Health, Social Services and Public Safety.

Recommendation 57 A commissioning requirement of any service that includes people with a learning disability must be the evidence from providers across departments and agencies of how information will be provided in an accessible format appropriate to the needs of the individuals being supported.

Recommendation 58 Health and Social Services Boards should be required, within a regionally agreed framework, to establish mechanisms in partnership with their service providers for monitoring the degree to which Person Centred Planning is appropriately implemented and delivers on positive personal outcomes for individuals with a learning disability.

Recommendation 59 The Health and Personal Social Services Regulation and Improvement Authority should include measurement in the standards against which learning disability services are inspected of the processes used in service delivery to secure positive personal outcomes.

Recommendation 60 A commissioned programme of research and service evaluation to support the implementation of the Equal Lives Review should be established in collaboration with the Research and Development Office.

ENABLING CHANGE: STAFFING

Chapter 11

> “ ”
>
> *All staff who work with people with a learning disability should get special training so that they understand how to respect people and know what to do to support people with a learning disability.* (1)

11.1 The biggest single contributor to quality services is the competence of the staff, both paid and unpaid, who are employed in them. Throughout the Equal Lives Review we have heard how people's lives have been enhanced by the relationships they have formed and the support they have received from the staff with whom they have come in contact. Since the last review of policy in 1995 there have been considerable changes that impact on developing a competent workforce in health and social care services:

- the volume and range of services has expanded creating a need for an extension to the workforce within and beyond health and social services
- an increase in the input of Direct Support Workers and an expanded range of roles that they undertake
- an increase in the numbers of Direct Support Workers employed on a part-time basis
- new or increasing demands arising from the changing demography and complex needs of people with a learning disability including:
  - addressing issues associated with working with an ageing population
  - increasing numbers of people with both an Autistic Spectrum Disorder and a learning disability
  - growth in number of children and adults who have complex physical health care needs.

11.2 Consultation conducted as part of the Equal Lives Review highlighted a range of positive characteristics in relation to developments in the workforce in response to these changes.

- Staff are increasingly developing approaches based on working with rather than for people with a learning disability and their families.
- There is now a higher profile for learning disability services, which has contributed to raising the confidence and status of staff in these services.
- The new and changing roles have created new opportunities for staff and have in many cases resulted in innovative service responses to staff training and development.

- The introduction of the Learning Disability Awards Framework (LDAF) has offered a coherent learning pathway for many Direct Support Workers in residential and day services in the WHSSB and in a growing number of voluntary agencies in Northern Ireland.

- Many individuals reported that there has been skills improvement amongst staff in learning disability services and an increased focus on their training.

11.3 The availability and retention of an appropriate range of qualified and competent staff will be crucial to the successful implementation of the Equal Lives Review. In this chapter we will explore the key factors that will impact on achieving this and outline our recommendations on the action required to build on the significant strengths that are currently in place amongst those who work with people with a learning disability and their families.

Objective 10	To ensure that health and social care staff are confident and competent in working with people with a learning disability.
Objective 11	To ensure that staff in other settings develop their understanding and awareness of learning disability issues and the implications for their services.

Issues and Concerns

User Involvement

11.4 Potentially one of the most powerful ways of raising awareness of the needs and aspirations of people with a learning disability and their family carers is to ensure their involvement in staff recruitment and development.

- During the Equal Lives Review we learned of a number of initiatives in this area, albeit that they are occurring in isolation from broader workforce strategies.

- Our understanding of the issues was greatly informed by the many presentations we heard from people with a learning disability and family members.

- This is an area that should be promoted more widely in agencies.

Recruitment and Retention

11.5 The recruitment and retention of staff is a key challenge for services both in Northern Ireland and throughout the United Kingdom.

- There is a lack of accurate data on either the current workforce or future workforce requirements on which to effectively develop strategies to address recruitment and retention difficulties.

- Staff in existing learning disability hospitals will have an important role to play within community based settings as the number of people living in hospitals reduce.

- 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 be 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 disability may not be presented as an attractive career pathway. Similarly difficulties appear to exist in recruiting staff to clinical psychology posts. Applications to learning disability nurse training have been reducing and by tradition there have always been fewer recruits to this branch of the profession.

- 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.

- There are clear benefits in achieving a cohesive and experienced staff group. These include increased continuity within services; a growth in staff skills and knowledge with experience and it offers a greater return on the investment in training and reduced costs of recruitment. (157)

- The most comprehensive review of literature relating to the retention of staff within community based services for people with a learning disability within the United Kingdom and the USA identified 8 key factors that have been consistently reported as contributing to staff turnover in learning disability services. (158) 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.

11.6 A wide range of factors have been highlighted that contribute to staff remaining in services, awareness of which can inform the development of a strategy to address retention difficulties. Key factors include effective stress management in the workplace, enabling a good work/life balance, effective support from managers and clarity about roles and responsibilities. (157, 158)

Volunteers

11.7 A much-neglected area of study is the role that unpaid volunteers play in supporting people with a learning disability.

- The invaluable contribution made by family carers who still provide the vast majority of support has been highlighted throughout the Equal Lives Review. Although it is impossible to accurately assess this financially, when it has been done for all carers in Northern Ireland (159) 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.

- 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. (160)
- Volunteers who give freely of their time to support people with a learning disability make a significant input particularly in the area of leisure and sporting activities e.g. approximately 4,000 men, women and children with a learning disability participate in leisure clubs in Northern Ireland such as Gateway and Special Olympics, which are staffed mainly by volunteers. (56)
- There will be an increased need for volunteer involvement as a consequence of the rise in advocacy and befriending services anticipated in the Equal Lives Review.
- The distinction between volunteers and paid staff can be blurred in fostering and family placement schemes in which a host family looks after a person with a learning disability in their home. Payments are made to cover the extra expense this entails although there is criticism of the low rates of pay on offer. However, most volunteers in these schemes do not want to make money but continue because of the satisfaction and enjoyment they get from it. (101)
- 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 4 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. (161)
- In sum, volunteers are in danger of being overlooked as services become more professionalised. Yet this is one of the proven means of reducing the social exclusion of people with a learning disability and for increasing the quality of their lives. Increased resources and efforts are required to sustain and expand schemes that support volunteers.

Changing Nature of Services

11.8 The changing nature of services detailed at paragraph 11.1 creates challenges and opportunities for workforce development including a trend towards smaller staff teams in services, an increase in lone working, a requirement that staff develop their understanding of the impact of Autistic Spectrum Disorder on people who have a learning disability and the need for training to enable staff to provide highly specialist health interventions.

- The increase in the number of people with a learning disability with additional complex health needs has created a need for additional supports and services if people are to be able to avail of the service provision. Increasing complexity of need in community care with added chronic disease management is currently placing under resourced community health services under great pressure.

> *My daughter is profoundly disabled and needs 24-hour care. The agency that provides respite in my house has been told their staff are not allowed to give her medication. I have to come home while they are there to give her the medicine so I don't really get the break at all.* (2)

- In many special schools this issue has been addressed by having more nurses on site during school time, which has been well received by education staff. (162) In day centres some nurses have been employed in other roles but until recently most centres have relied on inputs from nurses on the Community Learning Disability Teams. However, at least one Health and Social Services Trust has appointed a nurse to the day centre staff team; as yet there is no evaluation of the outcomes of this approach.

- Professionals are increasingly undertaking more specialist functions in services which requires them to move into new areas of work, new structures and new working methods for which training and staff support needs are particularly crucial.

- The concept of a Community Learning Disability Team has been a feature of learning disability services in the UK since the 1970s. The form and function of these teams varies widely and there has been very little research undertaken into the effectiveness of the various models despite the fact that they are an expensive component of health and social services provision. The structure of community teams providing services 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, 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 (163, 164), 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.

- Responses to consultation confirmed that there is a very variable pattern with some respondents indicating that they did not work in teams but rather as groups of professionals working alongside each other. Consultation feedback also confirmed the need for greater clarity about the composition and function of community teams and the changing role they should play in the future as a consequence of implementation of the Equal Lives Review.

- Ensuring the inclusion of people with a learning disability in community facilities will mean that some staff who support people with a learning disability will have to develop increased knowledge and skills in community profiling, community development and networking.

- As access to Direct Payments increases a larger number of individuals will be directly employing staff to meet their support needs creating new challenges in relation to meeting the training needs of both the employer and employees.

Staff in Mainstream Health Services

11.9 Despite the fact that inclusion has been a policy aim in Northern Ireland since 1995 (7), people with a learning disability continue to encounter persistent difficulties in gaining equity of access to mainstream services as noted earlier. In particular, difficulties have been reported in accessing primary care and acute general hospital services within Northern Ireland. To a large extent these stem from the attitudes of staff in these sectors.

- The views of professionals in primary care towards people with a learning disability and their limited skills in communication, limited preparation or specific training have been identified as factors influencing the service provided to people with a learning disability. Research evidence also shows that people with a learning disability often do not avail of other health services within community settings (eg dentist, optician, audiologist, speech and language therapist, dietician - refer to Chapter 7).

- 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 has identified the care of people with a learning disability in general hospitals as one of their top priority issues. (165)
- Studies consistently report limited confidence and uncertainty about what to do in working with people with a learning disability. Acute care 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 a physical disability. (166)
- Evidence is available from within Northern Ireland 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.

11.10 It will be equally important that staff in mental health services become more skilled in supporting people with a learning disability.

Training and Development

11.11 Whilst many people consulted during the Equal Lives Review highlighted an increase in the range of training and development opportunities available, concern was expressed about the patchy nature of such provision and the relevance of current qualifications to those supporting people with a learning disability.

11.12 Surveys of managers in learning disability services in Northern Ireland have consistently highlighted challenges for them in meeting the training and development needs of Direct Support Workers. Specific training gaps cited include staff training on sexuality and personal relationships, Autistic Spectrum Disorder and addressing challenging behaviours. (135, 136, 167) While the value is acknowledged of National Vocational Qualifications (NVQ) in assessing competence, shortcomings have been identified with current training requirements that focus solely on NVQ attainment without ensuring adequate provision of a coherent learning pathway for staff working with people with a learning disability. The introduction of LDAF has enabled agencies to begin to address this gap and initial evaluations of pilot projects using this framework are promising. (168)

11.13 The only dedicated professional training courses in learning disability are in nursing and psychiatry. Other professionals may take a number of modules or only parts of a module on learning disability as part of their initial training. The University of Ulster has recently introduced a Higher Certificate in Health and Social Care (Learning Disability Studies) although this is primarily intended for staff without formal professional training. There is a need to develop trans-disciplinary postgraduate modules or courses in the field of disability generally or learning disability in particular in order to increase the expertise of professionals working in dedicated learning disability services. The University of Ulster has recently introduced two such courses, one focusing on learning disability and challenging behaviours and the other on learning disability and mental health needs.

Action Required

11.14 The challenges to developing the workforce that will be required to achieve the Equal Lives objectives may be summarised as building a workforce that:

- meets the needs of people with a learning disability and their families
- recognises cultural shifts in services towards supporting people in ways that are person centred, more flexible and based on the Equal Lives values
- addresses problems in staff recruitment and retention
- is sensitive to the particular issues in working with people from ethnic minority communities
- comprises staff who are skilled, confident, competent and well supported by their employers
- develops the capacity of staff in learning disability services to provide leadership within and between a wide range of agencies.

11.15 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 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 with staff in these sectors.

11.16 Such collaborative arrangements should be evaluated against the degree to which they result in an increased capacity among mainstream services to support people with a learning disability and must replace families of people with a learning disability or staff in learning disability services providing parallel services to those provided to the wider population.

11.17 The collaborative developments noted above in relation to primary and acute care services will also be necessary for staff in a wide range of other services, such as employment support, further education and housing services; the key point being that the Equal Lives objectives will never be achieved if the knowledge, skills and values are not in place within all mainstream services.

11.18 Health and Social Services Boards and Trusts need to develop greater clarity about the coordination of community learning disability professionals. There is a confused picture at present, which does not form a viable basis for meeting the Equal Lives objectives. In particular for developing the revised working practices that will deliver the new styles of services envisaged in this report. The functions and coordination of community learning disability professionals should therefore be reviewed in light of the proposals in this review by December 2006. **(Recommendation 61)**

11.19 As a matter of urgency the Department of Health, Social Services and Public Safety should develop a regional development strategy for the learning disability workforce. This short-life review should be completed by April 2007. We believe that this strategy should:

- involve all key stakeholders including those in the independent sector
- review the remuneration of staff in relation to other service sector occupations, such as the hospitality industry

- seek to address the needs of small-scale isolated providers
- ensure that the current and future needs of the workforce are addressed particularly the implications for staff in addressing the direction of travel envisaged in this review
- promote increased joint working in addressing training and development needs
- promote the involvement of people with a learning disability and family carers in staff recruitment, training and development
- gather robust data on the workforce including current staff, qualifications held and identification of gaps in the knowledge and skills
- explore the potential application of LDAF for providing a learning pathway that complements NVQs and for up-skilling the learning disability workforce and staff in other settings. **(Recommendation 62)**

11.20 The Department of Health, Social Services and Public Safety currently operates the Training Support Programme (TSP), which provides funding for employers of social care staff in the statutory and voluntary sectors to enable them to meet the training requirements of Government policy. TSP has considerable potential to be used to support the training and development issues for these staff that have been highlighted in the Equal Lives Review. However, criteria for accessing this funding is rigidly linked to attainment of qualifications as determined by the Social Services Inspectorate and the Northern Ireland Social Care Council (NISCC). As has been noted these rigid qualification targets are seen as not being effective in meeting the full range of training challenges that exist in services and that will be exacerbated by the demands of the Equal Lives Review. The role of TSP needs to be revised, the budget available needs to be increased and the criteria for the funding revised in order to support the extensive workforce development challenges we envisage.

11.21 In order to support the involvement of service users in training those in receipt of TSP funding should be required to report on the degree to which they are developing mechanisms for securing the involvement of people with a learning disability in the design and/or delivery of training programmes. **(Recommendation 63)**

11.22 The training needs of family carers and volunteers have not been well met by existing arrangements. It should be incumbent upon those in receipt of TSP funding that mechanisms are set in place to open up access to this provision for these groups where possible. **(Recommendation 64)**

11.23 Finally there needs to be a time limited initiative to promote the leadership and managerial capacity of staff that will be crucial to the implementation of the Equal Lives Review. Priority should be given to proposals for initiatives that will be jointly planned across sectors and settings. **(Recommendation 65)**

11.24 In order to achieve a baseline level of knowledge that may be expected of all Direct Support Workers in adult learning disability services in Northern Ireland, it is recommended that the induction and foundation standards that have been produced by the NISCC become a mandatory requirement of all new entrants to this workforce. In order to ensure that the knowledge base is sensitive to the needs of men and women with a learning disability the attainment of these standards should be assessed through successful completion of LDAF induction and foundation standards as these have been developed with this aim in mind.[9]

11.25 From 1st January 2007 all new Direct Support Workers in learning disability services should be required to meet NISCC standards on induction and foundation within the 6 months of appointment. It is anticipated that this will normally be evidenced by completion of assessment to LDAF standards and be subject to inspection by Health and Personal Social Services Regulation and Improvement Authority (HPSSRIA). **(Recommendation 66)**

11.26 In order to produce health gains for people with a learning disability, to promote improved access to mainstream health and social services and to address the deficiencies that have been highlighted in professional training, we recommend that professional training is required to ensure that generically trained health and social services professionals (medicine, Allied Health Professionals, nursing, social work) should receive a minimum of awareness raising training on learning disability issues during their pre-qualification education. **(Recommendation 67)**

11.27 In order to enhance the status of working with people with a learning disability as a positive career choice and to encourage recruitment in the paid workforce, volunteering and community service, a publicity strategy should be developed and implemented that promotes the positive features of working with people with a learning disability. **(Recommendation 68)**

11.28 As has been noted throughout the Equal Lives Review successful community integration will require that members of the public and staff in agencies beyond health and social services develop a greater understanding of the strengths, needs and contribution that people with a learning disability can make to community life. In order to stimulate the development of such an understanding it is proposed that Department for Social Development, Department of Education and Department for Employment and Learning identify tangible action that they can take to promote joint training and awareness raising amongst the agencies that are accountable to them. **(Recommendation 69)**

11.29 Objectives 10 and 11	**Recommendations**
Recommendation 61	HSS Boards and Trusts should agree the role, composition, configuration and functions of Community Learning Disability Teams in light of the proposals in the Equal Lives Review by December 2006.
Recommendation 62	By April 2007 a regional workforce development strategy should be produced in partnership with employers from the independent and statutory sectors that identifies the workforce implications of the Equal Lives Review and sets out a clear strategy for addressing them.
Recommendation 63	All service providers who receive funding from the Department of Health, Social Services and Public Safety Training Support Programme should be required to evidence how people with a learning disability have been involved in the design, delivery and/or evaluation of training programmes provided on learning disability specific issues.

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[9] Work is ongoing on extending the LDAF to children's services. It will be necessary when this work is completed to consider its relevance and application to children's services in Northern Ireland

Recommendation 64 Service providers who receive Training Support Programme funding should be required to demonstrate that arrangements are in place to open access to the training provision to family carers, volunteers and people with a learning disability where possible.

Recommendation 65 Funding should be allocated to the Review Implementation Steering Committee for a Leadership Innovation Fund to which all agencies and professions might apply, designed to promote interagency initiatives that develop the leadership and managerial capacity in organisations to deliver on the new vision in the Equal Lives Review.

Recommendation 66 From 1 January 2007 all new Direct Support Workers in learning disability services should be required to meet the Northern Ireland Social Care Council standards on induction and foundation within the first year of appointment. It is anticipated that this will normally be evidenced by completion of assessment to LDAF standards and be subject to inspection by the Health and Personal Social Services Regulation and Improvement Authority.

Recommendation 67 All generically trained health and social services professionals (medicine, Allied Health Professionals, nursing, social work) should receive at a minimum awareness raising training on learning disability.

Recommendation 68 A publicity strategy should be developed and implemented that promotes the positive factors of working with people with a learning disability and encourages greater participation in volunteering and community service.

Recommendation 69 Department of Education, Department for Social Development and Department for Employment and Learning should develop measures to encourage awareness raising and improved training on learning disability amongst agencies that they fund to support equity of access by people with a learning disability to their provision. These measures should include the development of joint training opportunities with health and social services agencies.

MANAGING CHANGE: IMPLEMENTATION

Chapter 12

Improved inter-agency working would result in better service provision to those with a learning disability and an enhancement of their opportunity and quality of life.
Manager of a Citizens Advice Bureau.

12.1 The Equal Lives Review sets out an ambitious change programme that will require commitment and leadership at all levels in organisations throughout Northern Ireland. We anticipate that the implementation of the recommendations of the Equal Lives Review will involve a fundamental shift towards more person centred ways of working and a determined effort to remove barriers to inclusion in existing structures, systems and working practices. The Equal Lives Review has concluded that many of the aspirations in the 1995 Review were appropriate and that it can usefully be built upon to deliver on the Equal Lives objectives. However, our consultation indicates that major weaknesses in the 1995 Review included:

- the absence of transparent resource commitments to implement the Review's recommendations
- the lack of a robust implementation process
- the continuation of organisational impediments to progress.

12.2 Many of the needs of people with a learning disability and their family carers are best met at an individual, face-to-face level. However, the way in which these services are delivered is heavily influenced by the organisational structures in which they are provided. Different organisations can be involved in attempting to meet the diversity of needs and aspirations. Agencies have different funding sources as well as different management and staffing structures and contrasting ways of working. Therefore, it can be difficult for them to co-ordinate their services even when they are working in the same geographical area. These difficulties are further compounded when service priorities are set and service planning is undertaken without consultation with potential partner agencies.

12.3 In this chapter we will highlight issues and concerns relating to organisational arrangements in support of people with a learning disability and outline our proposals for supporting the implementation of the Equal Lives Review.

Objective 12 To promote improved joint working across sectors and settings in order to ensure that the quality of lives of people with a learning disability is improved and that the Equal Lives values and objectives are achieved.

Issues and Concerns

Organisational Structures

12.4 There is a wide range and growing number of organisations that work to support citizens in Northern Ireland. Many of these organisations are for everyone and therefore, they should be open to supporting people with a learning disability. Others are specific to people with a learning disability and in recent years their number has also grown significantly.

12.5 Some organisations have a regional remit in that they cover all of Northern Ireland. Others are responsible for designated geographical areas such as Health and Social Services Boards, while others cover particular districts, such as Health and Social Services Trusts or District Councils. Finally there are others, which work at a more local level, such as a special school or a day centre.

Present Service Structures For People With A Learning Disability

12.6 All Government departments have responsibilities to people with a learning disability just as they have to all other citizens. This responsibility was reinforced by Section 75, Northern Ireland Act (1998), which placed a duty on public authorities to have *due regard to the need to promote equality of opportunity between persons with a disability and persons without.* The Department of Education and Department of Health, Social Services and Public Safety have traditionally taken a leading role in addressing the needs of people with a learning disability for whom they have specific legal responsibilities. On occasions this has had an adverse effect in terms of limited impetus in other Departments to ensure that their activities effectively targeted people with a learning disability.

12.7 While a number of voluntary organisations also operate at a regional level there are no regional organisations led and managed by people with a learning disability.

12.8 The Department of Health, Social Services and Public Safety and Department of Education oversee the work of 4 Health and Social Services Boards and 5 Education and Library Boards at an area level. Unfortunately the geographical areas covered by these sets of Boards are not the same. Within Health and Social Services Boards, there are a number of programmes of care, of which learning disability is a distinct programme. However, other programmes of care also have some responsibility for people with a learning disability as they do for all other citizens although this is often not well defined. Likewise, each Education and Library Board has a senior manager with responsibility for Special Educational Needs.

12.9 The Boards act largely as planning and commissioning bodies; contracting with local agencies - that is Health and Social Services Trusts and Schools - to directly provide services.

12.10 Health and Social Services Trusts in turn may contract with voluntary and private sector providers for the delivery of certain services that usually cover a particular locality. Some of these agencies also work in different Trust and Board areas.

12.11 A number of organisations exist to further collaboration and co-ordination among the voluntary sector throughout Northern Ireland. These include the Association of Real Change (ARC), Children in Northern Ireland and Northern Ireland Council for Voluntary Action (NICVA).

Participation by People with a Learning Disability or Carers in Service Planning and Provision

12.12 There are few formal organisations to represent the views of people with a learning disability or family carers. Consequently there is little tradition of service providers working jointly with people with a learning disability or family carers in the provision of services.

- There is general agreement that greater participation in the planning of learning disability services would result in better services.
- There is a greater emphasis on consultation rather than participation, where consultative processes are separated out from Trust business planning arrangements.
- The value of integrating consultative processes with policy development mechanisms has been evidenced by the role played by Equal Lives group members in the Equal Lives Review, which clearly demonstrated their capacity to be active participants in the process with strongly held views on topics that may receive less attention from professionals. (1)

Reform of Public Administration in Northern Ireland

12.13 A major Review of Public Administration (RPA) commenced in June 2002. The RPA has highlighted a common concern about

> *a continuing growth in the number of organisations involved in public administration, which not only absorbs resources, but makes it more difficult for the public to identify and contact the appropriate source of advice and support and a lack of co-ordination between sectors and organisations at all levels where there is a need to work together on specific issues or personal cases.* (169)

12.14 The RPA team has published its final stage consultation document. A two-tier model is proposed, with a regional tier encompassing the Assembly, Government departments and regional authorities. The second, sub-regional tier covers organisations that would ideally have the same boundaries, including councils, health bodies, other sub-regional bodies and sub-regional delivery units of regional bodies. There is also support for an enhanced role for both the private sector and the voluntary and community sectors. Given the significant changes to the structure of the public sector in Northern Ireland, that are proposed by the RPA, we consider it premature to recommend far reaching changes at this stage. Rather we will set out considerations that we hope will help inform the future reform process.

Developing Policy for Learning Disability Services in Northern Ireland

12.15 Despite the growing emphasis on joint working in Government policy statements, the main method of service planning and delivery in support of people with a learning disability remains that of independent working by different agencies.

12.16 In the 1995 Review of Policy for People with a Learning Disability, it was noted that other Government departments and agencies have a lead role to play, such as housing, further education, training for and support in employment, and leisure. It recommended

Good liaison arrangements between all of the agencies involved are necessary both at the strategic planning level and at the point of service delivery to ensure the development and implementation of compatible and co-ordinated strategies. (7)

12.17 As has been noted throughout this report the Equal Lives Review has identified serious shortcomings in achieving this aim.

12.18 In recent years the Department of Health, Social Services and Public Safety has identified the need for inter-departmental working to meet a range of Government policy objectives in the broad field of health and various interdepartmental working groups have been set up in furtherance of these aims; most notably the Ministerial Group on Public Health. (170) However, formal interdepartmental working appears not to have occurred to any great extent in learning disability, although there have been positive developments in relation to interdepartmental groups on Early Years and Transitions, which have addressed the needs of young people and children with a disability.

12.19 Since the last Review of Learning Disability Services all 4 Health and Social Services Boards have produced policy statements on service provision. All Boards endorsed the need for inter-sectoral working with voluntary and statutory providers and also for consultations and planning to be done with service users and family carers.

12.20 A study carried out by the University of Ulster for the Equal Lives Review confirmed that joint working is happening to some extent on the ground. The benefits were seen to outweigh any potential drawbacks and they centred mainly on the gains for people with a learning disability in getting better co-ordinated services. This implies recognition that services working independently of one another are providing a poorer quality of service than they could be delivering.

12.21 The research study confirmed the messages from other submissions made to the Equal Lives Review that there will need to be a determined and committed effort to ensure that joint working is an essential feature of future service provision in Northern Ireland. In addition, our review of work undertaken to implement changes to policy affecting people with a learning disability elsewhere in the UK and the Republic of Ireland confirms that robust implementation arrangements are essential if the changes are to succeed.

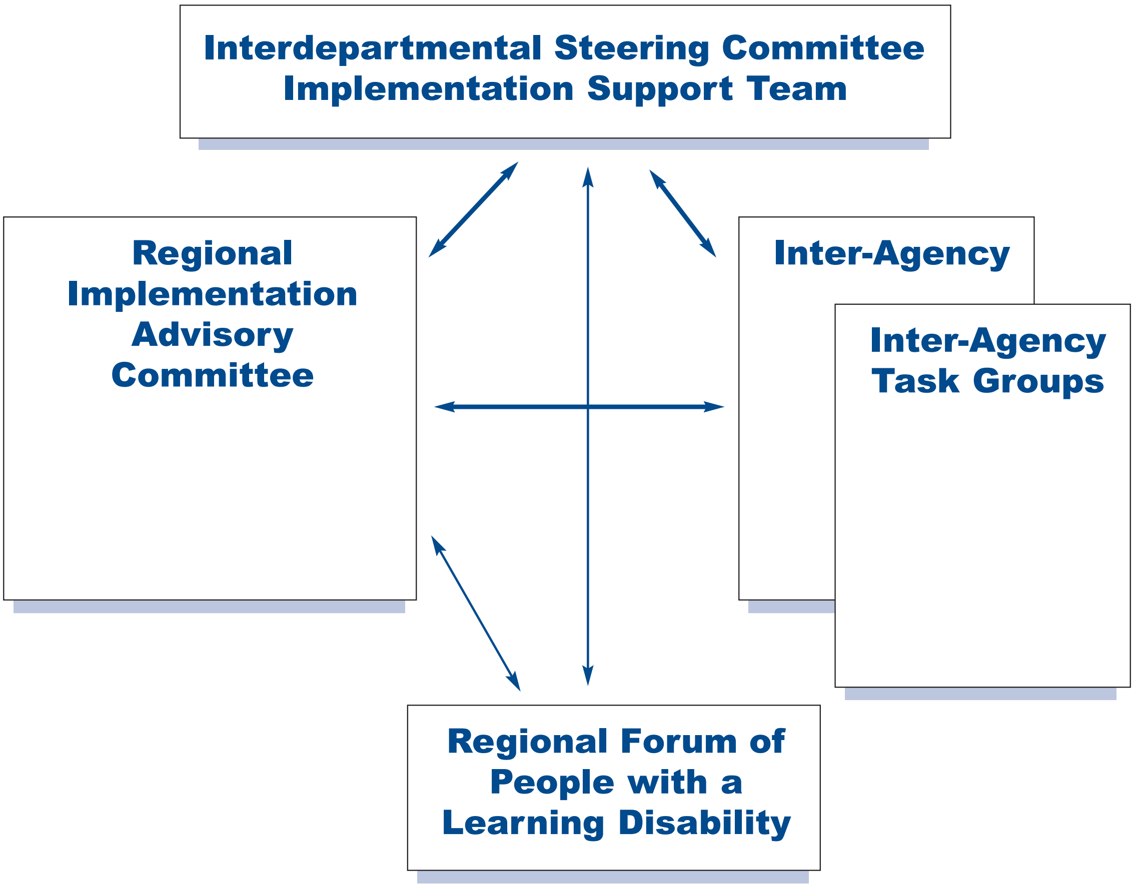
12.22 The proposals that follow acknowledge that, in the context of the RPA, there is a need for us to highlight principles that should underpin any future restructuring to ensure that the needs of people with a learning disability and indeed other minority groups are addressed. These proposals are, therefore, offered to inform the ongoing work of the RPA unless accompanied by a specific recommendation that we believe should be enacted regardless of the nature of restructuring that will follow the outcomes of the RPA.

Action Required

Review Implementation Arrangements

12.23 The Equal Lives Review has highlighted a need for a major development of services and some reconfiguration of existing provision. In Figure 12 we outline the structures that we believe are required to ensure that this happens effectively and in accordance with the core values of the Equal Lives Review. This model aims to facilitate the processes of consultation, co-ordination and implementation, which arguably are missing in existing structures.

Figure 12: Proposed Implementation Arrangements



12.24 Particular efforts need to be made to promote the meaningful involvement of people with a learning disability in future arrangements. At present the number of organisations doing this is small, as is the development of advocacy in its various forms. There is no regional forum for people with a learning disability in Northern Ireland and very limited public money is spent on the promotion of advocacy and in supporting people with a learning disability to participate meaningfully in planning groups and committees. Moreover there is a need to promote advocacy at a more local level as well, so that people with a learning disability have increased opportunities to access mainstream as well as specialist services.

12.25 The involvement of carers is arguably further advanced in service planning, but this is variable across Northern Ireland. When it has occurred, the outcomes are broadly positive, which should encourage provider and commissioning agencies to expand their engagement with carers. This can be achieved by ensuring they are represented alongside professionals in committees and working groups. It is vital though that these representatives are assisted in ensuring the broader population of carers are informed of these processes and that mechanisms are in place to reflect their views.

12.26 There are a number of clear messages to emerge from the Equal Lives Review about how joint working can be promoted. These are already operational in Northern Ireland, albeit in contexts other than learning disability, but they do have the support of the agencies consulted as part of the Equal Lives Review. We anticipate that there is a need for 2 levels of joint working: inter-departmental and local inter-agency. This simple structure should suffice given the size of Northern Ireland and the small number of people with a learning disability.

12.27 Moreover it is important that these structures incorporate the 3 processes of consultation, co-ordination and implementation.

12.28 There is widespread agreement on the benefits of having an Interdepartmental[10] group to take forward the recommendations emerging from the Equal Lives Review. Membership of this Interdepartmental Steering Committee would comprise representatives from each relevant Government Department. The Minister should chair the meetings of the Interdepartmental Steering Committee on 4 occasions per annum. **(Recommendation 70)**

12.29 The Interdepartmental Steering Committee would also have responsibility for advising Departments on the commissioning of both existing and new learning disability services. In doing so they would be informed by representatives of users, carers, local Inter-Agency Task Groups and service providers who would comprise a Regional Implementation Advisory Committee. The Regional Implementation Advisory Committee would provide an opportunity to identify common issues across Northern Ireland, as well as sharing in good practice initiatives. It would monitor the work of the local Inter-Agency Task Groups as well as provide a forum for debate on controversial issues and on the development of new service initiatives envisaged by the Equal Lives Review. The work of the Regional Implementation Advisory Committee should be supported by a Development Fund to stimulate change and innovation in the implementation of the Equal Lives Review.

12.30 Both committees would need to be serviced by a small team of full-time staff - an Implementation Support Team - preferably to include staff seconded from agencies outside of the Civil Service, who have particular experience and expertise in assessing and meeting the needs of people with a learning disability and who can provide credible advice and guidance to local groups in the production and implementation of local plans and change initiatives. **(Recommendation 71)**

12.31 There may also be some value in designating one person with lead responsibility for the operations of this team, who is accountable (has direct access) to the Minister chairing the Interdepartmental Steering Committee.

12.32 The Regional Implementation Steering Committee and Implementation Support Team would liaise closely with a Regional Forum for People with a Learning Disability. They would produce accessible annual reports and meet the Forum at least annually to plan the programme of work for the coming year. **(Recommendation 72)**

12.33 The Implementation Support Team could be time-limited appointments for a 5-year period in order to establish the new structures and to help them to bed down. The ultimate goal would be for these new arrangements to become embedded into mainstream structures, although the need for an interdepartmental group would probably continue as would the Regional Forum for people with a learning disability.

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[10] At a minimum this should consist of DHSSPS, DENI, DEL, DSD, OFMDFM and Department of Culture, Arts and Leisure (DCAL).

12.34 These joint working arrangements should be replicated at a local level. Inter-Agency Task Groups should be set up at an agreed local level. Initially we propose that 4 Task Groups be established possibly based on existing Health and Social Services Board areas, which may sub-divide for particular purposes such as supporting the production of Day Care Development Plans. **(Recommendation 73)**

12.35 The Inter-Agency Task Groups' remit would be to review existing provision in their area and to plan the range of services available to people with a learning disability and their families within the context of the Equal Lives values and objectives. These groups could cover the full age range of people with a learning disability, although they will need to liaise with the 4 area inter-agency groups that are already operational for children's services if they continue in operation.

12.36 The Inter-Agency Task Groups should have representatives of existing statutory, voluntary and private agencies and would include Health and Personal Social Services, Education and Library Boards, Further Education Colleges, Department for Employment and Learning, Northern Ireland Housing Executive, Community Education and Leisure Services of District Councils, along with user and carer representatives and their advocates. Initially they would be convened and supported by Health and Social Services Boards, but within 1 year, the groups will have identified the means for achieving co-ownership.

12.37 The groups would be required by the Interdepartmental Steering Committee to prepare Joint Learning Disability Service Plans along the lines of those required in Great Britain and the Republic of Ireland. These will form the basis of funding bids and the commissioning of local services. They would also inform the form, role and location of specialist learning disability provision and access to other special needs services.

12.38 The proposed Implementation Support Team and the Regional Implementation Advisory Committee would have a major role to play in establishing and supporting these groups.

North-South and East-West Relationships

12.39 This proposed structure would also facilitate greater linkages with learning disability interests elsewhere in these islands; notably between the Governmental Interdepartmental Groups and between the different national fora for people with a learning disability.

12.40 Indeed it could be argued that the lack of these structures within Northern Ireland has contributed to the relative isolation of learning disability services here from elsewhere in these islands.

Specific Focus on Learning Disability

12.41 There has been a long history in Northern Ireland of ring-fencing public funding to services specifically for people with a learning disability. Ring-fenced funding can be justified on various grounds. The needs of this population are complex and life-long even though the numbers are relatively small. Moreover they are distinctive when taken as a whole especially from other disabling conditions and mental health needs. Services are still under-developed and development monies are more easily targeted if they have a specific focus. Major changes in policy are more easily implemented within a distinct domain.

12.42 We recommend that ring-fenced funding continues within the Department of Health, Social Services and Public Safety and Department of Education, even though the way in which these monies are spent could change radically in the coming years as they have done in the past. This also necessitates having transparent accountability systems in place to demonstrate that the monies are spent on the purposes for which they were given and the outcomes achieved.

12.43 There is also logic in extending this concept to other funding departments, especially in the light of Section 75 duties placed upon public bodies. At a minimum this would demonstrate that these citizens are getting at least their fair share, but also make more transparent the contribution they are making to positively responding to the particular needs of these citizens. **(Recommendation 74)**

12.44 This is not to imply that these funding streams should be managed separately. Indeed the evidence suggests that local services can be more efficiently delivered if they are jointly commissioned using pooled funding, as is the case in Great Britain. This is starting to happen with the new Supporting People arrangements in Northern Ireland and this model could be extended to other aspects of people's lives such as transition planning, training and employment services, and leisure initiatives.

12.45 In view of the negative impact that the absence of robust implementation structures had on the success of the 1995 Review, it is the view of the Learning Disability Working Committee that work on implementing each of the following recommendations has to be commenced immediately if the objectives of the Equal Lives Review are to be achieved.

12.46 Objective 12	**Recommendations**
Recommendation 70	An Interdepartmental Steering Committee should be established by January 2006 to promote joint working and oversee the implementation of the Equal Lives Review recommendations.
Recommendation 71	An Implementation Support Team should be established by November 2005 to support work being undertaken to implement the Equal Lives Review.
Recommendation 72	A Regional Forum for People with a Learning Disability should be established by January 2006.
Recommendation 73	Inter-Agency Task Groups should be established by June 2006 to drive change at a local level and produce local plans in accordance with the Equal Lives values and objectives.
Recommendation 74	Ring-fenced funding continues within Department of Health, Social Services and Public Safety and Department of Education and the potential is explored for extending this to other departments to underpin the implementation of the Equal Lives Review.

Prioritisation of Other Recommendations

12.47 This report has highlighted that people with a learning disability in Northern Ireland do not enjoy equality of opportunity and that they are often excluded from the opportunities that other citizens enjoy. As has been shown some progress has been made but in order to resolve fully the difficulties outlined there will be a need for a major and co-ordinated development programme over the next 15 years.

12.48 The Equal Lives report has made 74 recommendations to take forward its vision for the future. Full implementation of these recommendations will cost approximately £175 million additional over the change period. (171) It is recognised that these large sums of money are not immediately available and accordingly this section of the Equal Lives report will set out some immediate and medium -term objectives. While change will be costly and will take time there must be an immediate and ongoing commitment to making financial resources available if the change process is to be real. While the report recognises the need to reconfigure and better target existing resources, the level of change and modernization envisaged will not happen without this commitment.

12.49 To maximise the impact of change it will be essential to progress each of the report objectives in tandem. While some recommendations will not require funding they will require considerable investment of planning time from staff and will also have to be incrementally introduced.

12.50 It is now intended to order each of the Equal Lives Review recommendations placing a priority rating against them. Priority ratings agreed were as follows:

i. Pre-Implementation Support

ii. Immediate Planning - to be started forthwith

iii. Immediate Resourcing - 2006 - 2012

iv. Medium-term Resourcing - 2012 - 2020.

Principles Guiding Prioritisation Process

12.51 Recommendations will be prioritised if they:

i. provide support for family carers

ii. maximise HPSS and other public funding streams e.g. Supporting People

iii. show that they can prevent inappropriate hospital admissions

iv. release money from current services which are considered to be no longer fit for purpose

v. promote effective access to all services across Northern Ireland

vi. maintain and build upon existing interagency collaborations.

12.52 It is clearly acknowledged that the recommendations are not mutually exclusive and therefore planning for delivery of all the recommendations must commence immediately. The Learning Disability Working Committee accept that implementation of all the recommendations by necessity will be incremental in nature.

Pre-Implementation Support

- Appointment of Implementation Support Team by November 2005
- Establishment of Interdepartmental Steering Committee by January 2006
- Establishment of Regional Forum for People with a Learning Disability by January 2006
- Establishment of Inter-Agency Task Groups by June 2006

- Agreement that ring-fenced funding continues within Department of Health, Social Services and Public Safety and Department of Education and the potential explored for extending this to other departments. **(Recommendations 71,70,72,73,74)**

Immediate Planning

12.53 Those recommendations that fit into Immediate Planning are as follows:

- Development of joint planning and bidding mechanisms by the Departments of Education and Health, Social Services and Public Safety for services for children and young people with a learning disability by January 2007
- Development of a regional strategy for early intervention by the Departments of Education and Health, Social Services and Public Safety by June 2007
- Promotion of Supported Employment Services by Department for Employment and Learning
- Clear assessments of future housing needs for people with a learning disability completed and agreement reached on a 3 year funding strategy to resource housing and support arrangements by Department for Social Development and Department of Health, Social Services and Public Safety
- Detailed knowledge accumulated and disseminated on the range of assistive technology that is available to enrich the capacity of people with a learning disability to lead more independent lives in the community by housing planners
- Development of a strategy to increase opportunities for people with a learning disability to own their own homes by the Department for Social Development
- Revised procedures and criteria for applying for Disabled Facilities Grants
- Mechanisms established to ensure the increased use of floating support by the Department for Social Development and the NI Housing Executive
- Review completed of the Motability Scheme
- Regional Framework for Health Improvement of people with a learning disability produced by the Department of Health, Social Services and Public Safety
- Equipment and wheelchair provision budgets increased to meet significant additional demand
- Health Improvement Plans reviewed by HSS Boards
- Specific reference to the needs of and impact upon people with a learning disability within all generic health strategies, published at Department, HSS Board and Trust level
- Awareness raising and improved training on learning disability in place amongst agencies funded by the Department of Education, Department for Social Development, and Department for Employment and Learning
- Commissioned programme of research and service evaluation established in collaboration with the R & D Office

- Identification of the need for permanent placements for children and young people with a learning disability and production of strategies by Health and Social Services Boards to address them by March 2006
- Costed Development Plans for day centres produced by each Health and Social Services Trust by March 2007

(Recommendations 9, 8, 18, 23, 32, 33, 34, 35, 36, 37, 38, 44, 68, 60, 4, 17)

Immediate Resourcing

12.54 The following recommendations have been agreed as falling within this area:

- Opportunity to have a PCP which incorporates Heath Action Planning is in place for all persons with a learning disability who are in contact with HPSS agencies by January 2009
- Arrangements in place from January 2006 to prioritise person centred planning concerned with:
  - development and delivery of Family Support Plans
  - development and delivery of Early Intervention Plans
  - Transitions Plans
  - Futures Plans
- Establishment of independent advocacy services
- Establishment of Family Support Fund and extension of range and volume of support available to families
- Development of community based assessment and treatment services for children and young people with severe challenging behaviours and/or mental health problems
- Mechanisms in place to ensure that information on services, benefits and other sources of help is automatically supplied to families at diagnosis/birth of their child
- Commissioning requirement in place detailing that providers of any services evidence how information will be provided in an accessible format appropriate to the needs of the individuals being supported
- Establishment of Transition Services for all young people who have a statement
- Personal relationships education available in all services for people with a learning disability with training offered to staff and support to parents
- Development of community based assessment and treatment services for men and women with a learning disability who have specific mental health needs and/or challenging behaviours
- Production of regional guidelines on the management of challenging behaviours within services by December 2007 by the Department of Health, Social Services and Public Safety in partnership with service providers
- All people with a learning disability living in a hospital relocated to the community by June 2011

- Funds provided to ensure that on average 80 people are resettled per annum over the 5-year period from 2006 to 2011
- Resourced and implemented arrangements in place to provide emergency support and accommodation for persons with a learning disability by January 2008
- Mechanisms in place to ensure that all new housing with support provision for people with a learning disability is for no more than 5 individuals with a learning disability within the same household
- Additional 100 supported living places per annum developed for the next 15 years to enable people to move from family care without having to be placed in inappropriate settings
- Clear and formalised arrangements set in place by each General Practice facility and Acute General hospital to facilitate equity of access to services for people with a learning disability
- Link person identified within Community Learning Disability Teams to work with each General Practice
- Establishment by General Practices of robust medical records and health data about people with a learning disability on their practice registers
- Strategic plan produced by the Department of Health, Social Services and Public Safety and HSS Boards to address current deficiencies in services and future service provision for older people with a learning disability and their families
- Development of arrangements to enable people with a learning disability who have dementia to access support and expertise from mainstream dementia services
- £300,000 per annum ear-marked by the Department of Health, Social Services and Public Safety between 2006 and 2009 to increase uptake of Direct Payments
- Policy initiative from OFMDFM in place to reduce the likelihood of bullying experienced by people with a learning disability
- Agreement reached by HSS Boards and Trusts on the role, composition, configuration and functions of Community Learning Disability Teams by December 2006
- Production of a regional workforce development strategy by April 2007
- Establishment of a Leadership Innovation Fund by the Interdepartmental Steering Group
- Arrangements set in place for all new Direct Support Workers in learning disability services to meet the Northern Ireland Social Care Council standards on induction and foundation evidenced by completion of assessment to LDAF standards by January 2007
- Mechanisms set in place for young people with a learning disability to be equipped with skills to use public transport where possible through appropriately targeted independent travel training programmes by Department of Education and Department of Health, Social Services and Public Safety
- Arrangements set in place to ensure that the regional transport strategy ensures that people with a learning disability can access local transport by the Department for Regional Development
- Arrangements set in place to ensure that access to local leisure and recreational services is promoted and co-ordinated led by District Councils

- Clear statements produced on targeting provision for play, sports, arts and leisure opportunities for children and young people with a learning disability by the Department of Culture, Arts and Leisure, Arts Council, Sports Council, Education and Library Boards, Youth Council and District Councils

- Review completed of the effectiveness of programmes of learning for children and young people with special educational needs in relation to issues of personal safety and personal relationships by the Department of Education and Education and Library Boards

- Arrangements made for mainstreaming lessons learned from the pilot projects on inclusion by the Youth Service

- Arrangements made for monitoring the effectiveness of all authorities in meeting their inclusion objectives for children and young people with a learning disability by the Commissioner for Children and Young People

- Revised funding arrangements set in place by Department for Employment and Learning so that FE Colleges are able to increase significantly the number of full-time places available to students who have a Statement of Severe Learning Disability, to undertake a 3 year accredited course

- Review completed of the use of employment, skills and disability programmes by people with a learning disability by Department for Employment and Learning

- Review completed by public sector employers of recruitment practices to open up employment opportunities for men and women with a learning disability

(Recommendations 54, 40, 56, 1, 2, 5, 57, 6, 7, 14, 25, 27, 47, 28, 29, 31, 41, 42, 43, 50, 52, 53, 55, 26, 61, 64, 65, 21, 22, 24, 10, 12, 13, 11, 15, 20, 19)

Medium term resourcing

12.55 The recommendations that fall into this area are:

- Establishment of multi-agency centres, which provide a clear pathway to help for parents of children with a learning disability by Health and Social Services Trusts in partnership with Education and Library Boards and the community and voluntary sector

- Revised funding arrangements set in place by the Department for Employment and Learning to enable more part-time places to be created in FE for older students

- Arrangements secured for all accommodation for people with a learning disability under 60 years of age to be for no more than 5 people by January 2013

- Resources made available from within primary care to appoint a Health Facilitator for each 110-120,000 population by December 2009

- Arrangements secured for the majority of referrals, because of mental health problems, of people with high levels of adaptive functioning/mild learning disability to access, with support from dedicated learning disability services if required, mainstream mental health services by December 2010

- Arrangements set in place by the Health and Personal Social Services Regulation and Improvement Authority to measure delivery of positive personal outcomes by services

- Arrangements set in place for all generically trained health and social services professionals to receive awareness raising training relating to people with learning disability during their pre-qualification education

(Recommendations 3, 16, 30, 39, 46, 59, 66)

Conclusion

12.56 We have set out an ambitious programme for change in the Equal Lives Review, which we believe sets out a clear policy direction for people with a learning disability. The Equal Lives values and objectives should form the benchmarks by which future policy and service developments are measured.

12.57 The objectives and recommendations that we have made cannot be met within current resources and organisational systems. There is a need to change both the use of existing resources and to secure additional funding if the Equal Lives objectives are to be achieved. In addition all those who work with people with a learning disability in both specialist and mainstream settings will need to review how they work, and where necessary, to develop new styles of working that are based on ensuring that the voices of people with a learning disability and their family carers have a greater influence and improved approaches to working in partnership.

12.58 The enthusiasm and dedication that has been evident from the many hundreds of people who have participated in the Equal Lives Review demonstrates that there is a strong commitment to improve the quality of lives of people with a learning disability and their families. The challenge now will be to ensure that the aspirations contained in this Review are translated into action across Northern Ireland in a way that ensures that people with a learning disability really can experience equal lives in the future.

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OBJECTIVES AND RECOMMENDATIONS

Annex A

OBJECTIVE 1 **To ensure that families are supported to enjoy seeing their children develop in an environment that recognises and values their uniqueness as well as their contributions to society.**

Recommendation 1 Each Trust should have established arrangements for the development of Family Support Plans, which must be delivered through a co-ordinated strategy that monitors outcomes and identifies unmet needs.

Recommendation 2 Over the next 5 years providers should be resourced to extend the volume and range of emotional and practical help to support families. Their proposals should be considered within the context of Children's Services Planning and be aimed at assisting the maximum number of families. An ear-marked fund of up to £2 million recurrent each year for 5 years should be made available to fund proposals that best meet the Equal Lives values and objectives. The outcomes from this Family Support Fund should be carefully evaluated and used to inform future commissioning decisions in support of family carers.

Recommendation 3 Health and Social Services Trusts in partnership with Education and Library Boards and the community and voluntary sector should establish multi-agency centres, which provide a clear pathway to help for parents of children with a learning disability.

Recommendation 4 By March 2006 each Health and Social Services Board should identify the need for permanent placements for children and young people with a learning disability and produce strategies to address them. While the focus should be on innovative means of developing and supporting specialist fostering, it may be necessary to commission intensive care provision for small numbers of children who can not be placed in family settings.

Recommendation 5 Community based assessment and treatment services should be developed for children and young people with severe challenging behaviours and/or mental health problems. The service should encompass a small short-stay residential provision and community behavioural support services that provide outreach to families, schools and community based agencies.

OBJECTIVE 2	**To ensure that children and young people with a learning disability get the best possible start in life and access opportunities that are available to others of their age.**

Recommendation 6	Each HSS Trust should set in place mechanisms to ensure that information on services and how to access them, benefits and support groups and other sources of help is automatically supplied to families at diagnosis/birth of their child.
Recommendation 7	Each HSS Trust should establish arrangements for the development of an Early Intervention Plan, which includes details of a key worker, for each child with a learning disability at his/her birth/diagnosis.
Recommendation 8	By June 2007 the Departments of Education and Health, Social Services and Public Safety should develop a regional strategy for early intervention.
Recommendation 9	By January 2007 joint planning and bidding mechanisms should be developed by the Departments of Education and Health, Social Services and Public Safety for services for children and young people with a learning disability.
Recommendation 10	The Department of Culture, Arts and Leisure, Arts Council, Sports Council, Education and Library Boards, Youth Council and District Councils should produce clear statements outlining how they are targeting provision for play, sports, arts and leisure opportunities for children and young people with a learning disability.
Recommendation 11	The Youth Service should mainstream the lessons learned from the pilot projects on inclusion and provide the support to ensure that young people with a learning disability get involved in decision-making processes in youth and other civic activities.
Recommendation 12	The Department of Education and Education and Library Boards should review the effectiveness of the programmes of learning for children and young people with special educational needs in relation to issues of personal safety and personal relationships. This should be supported with awareness programmes for parents and for others involved with children and young people.
Recommendation 13	The Commissioner for Children and Young People should be requested to monitor the effectiveness of all authorities in meeting their inclusion objectives. To facilitate this, the relevant departments should produce an Annual Report on the implementation of action plans.

OBJECTIVE 3	**To ensure that the move into adulthood for young people with a learning disability supports their access to equal opportunities for continuing education, employment and training and that they and their families receive continuity of support during the transition period.**
OBJECTIVE 4	**To enable people with a learning disability to lead full and meaningful lives in their neighbourhoods, have access to a wide range of social, work and leisure opportunities and form and maintain friendships and relationships.**

Recommendation 14	That Transition services are established for all young people who have a statement to support parents and young people to develop a transitions plan and ensure

recommendations are carried through. Careers advice restructuring should support this proposal and provide an ongoing support to 22 years.

Recommendation 15 The Department for Employment and Learning will ensure that revised funding arrangements are in place so that FE Colleges are able to increase significantly the number of full-time places available to students who have a Statement of Severe Learning Disability, to undertake a 3 year accredited course.

Recommendation 16 In order to afford lifelong learning opportunities the Department for Employment and Learning should ensure that revised funding arrangements will enable more part-time places to be created in FE for older students. Access to FE by people with a learning disability should be monitored and we welcome the intention of the Department for Employment and Learning to do so.

Recommendation 17 By March 2007 each Health and Social Services Trust should have produced a costed Development Plan for each day centre they provide or commission.

Recommendation 18 The Department for Employment and Learning, in consultation with other relevant Departments, should promote the introduction of dedicated Supported Employment services across Northern Ireland.

Recommendation 19 Public sector employers should review their recruitment practices, as required by equality legislation to open up employment opportunities for men and women with a learning disability.

Recommendation 20 Department for Employment and Learning should review the use of its employment, skills and disability programmes by people with a learning disability to remove structural barriers to participation and identify how they could promote better outcomes.

Recommendation 21 Department of Education and Department of Health, Social Services and Public Safety should ensure that young people with a learning disability are equipped with skills to use public transport where possible through appropriately targeted independent travel training programmes. Where possible these should become part of the curriculum and continuing education plans for young adults.

Recommendation 22 Department for Regional Development should ensure that the regional transport strategy ensures that people with a learning disability can access local transport.

Recommendation 23 The Motability Scheme requires reviewing to ensure an appropriate, affordable solution for those who need to travel in their wheelchair along with other family members.

Recommendation 24 Access to local leisure and recreational services should be promoted and co-ordinated led by District Councils.

Recommendation 25 Personal relationships education should be available in all services for people with a learning disability with training offered to staff and support to parents.

Recommendation 26 OFMDFM should co-ordinate a policy initiative to reduce the likelihood of bullying experienced by people with a learning disability, both in specialist settings and the wider community, notably schools. The development of anti-bullying strategies would be a positive first step.

OBJECTIVE 5 **To ensure that all men and women with a learning disability have their home, in the community, the choice of whom they live with and that, where they live with their family, their carers receive the support they need.**

Recommendation 27 By June 2011, all people with a learning disability living in a hospital should be relocated to the community. Funds need to be provided to ensure that on average 80 people will be resettled per annum over the 5-year period from 2006 to 2011.

Recommendation 28 With immediate effect, all commissioners should ensure that they have resourced and implemented arrangements to provide emergency support and accommodation for persons with a learning disability. Hospitals will not provide this service from 1st January 2008.

OBJECTIVE 6 **To ensure that an extended range of housing options is developed for men and women with a learning disability.**

Recommendation 29 With immediate effect, all new housing with support provision for people with a learning disability should be for no more than 5 individuals with a learning disability – preferably less - within the same household.

Recommendation 30 By 1 January 2013 all accommodation for people with a learning disability under 60 years of age should be for no more than 5 people.

Recommendation 31 An additional 100 supported living places per annum for the next 15 years should be developed to enable people to move from family care without having to be placed in inappropriate settings.

Recommendation 32 Department for Social Development and Department of Health, Social Services and Public Safety should develop clear assessments of future housing needs for people with a learning disability including those who currently live with their families and agree a continuous 3 year funding strategy to resource housing and support arrangements.

Recommendation 33 Housing planners should accumulate and disseminate detailed knowledge on the range of assistive technology that is available to enrich the capacity of people with a learning disability to lead more independent lives in the community.

Recommendation 34 A strategy should be developed by the Department for Social Development to increase opportunities for people with a learning disability to own their own homes where this is a safe and appropriate option.

Recommendation 35 Procedures and criteria for applying for Disabled Facilities Grants should be revised to tackle inconsistencies, reduce bureaucracy and reduce the hidden costs to carers.

Recommendation 36 Department for Social Development and the NI Housing Executive should establish mechanisms to ensure the increased use of floating support linked to an individual's needs rather than overly relying on accommodation based schemes.

OBJECTIVE 7 To secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability.

Recommendation 37 The Department of Health, Social Services and Public Safety should produce a Regional Framework for Health Improvement of people with a learning disability providing clear direction including targets and timescales. Each HSS Board should review their Health Improvement Plans to ensure that they translate the regional framework at a local level to support improved health outcomes for children, men and women with a learning disability.

Recommendation 38 All generic health strategies, published at Department, Board and Trust level, should make specific reference to the needs of and impact upon people with a learning disability.

Recommendation 39 By December 2009 resources should be made available from within primary care to appoint within primary care a Health Facilitator for each 110- 120,000 population.

Recommendation 40 By December 2008 a Health Action Plan will be developed, as a part of the Person Centred Planning process, which is to be set in place for all those with a learning disability in contact with health and social services agencies.

Recommendation 41 With immediate effect each general practice facility and acute general hospital within Northern Ireland should have clear and formalised arrangements in place to facilitate equity of access to services for people with a learning disability.

Recommendation 42 Each general practice should establish robust medical records and health data about people with a learning disability on their practice register.

Recommendation 43 With immediate effect each general practice should have an identified link person within their local Community Learning Disability Team with whom they work collaboratively to facilitate better access for people with learning disability within primary care settings.

Recommendation 44 Equipment and wheelchair provision budgets should be increased to meet significant additional demand. This will require an increase of the proportion available to people with a learning disability.

Recommendation 45 As a matter of urgency the Department of Health, Social Services and Public Safety should consult with all 4 Health and Social Services Boards about their present and future plans for specialist assessment and treatment services for men and women with a severe learning disability with a view to greater sharing of existing and planned resources and the development of new forms of community based services.

Recommendation 46 By the end of the Review period people with high levels of adaptive functioning/mild learning disability who require therapeutic intervention as a result of mental health problems should be able to access mainstream mental health services. Support from dedicated learning disability services should be available if required.

Recommendation 47 Community based assessment and treatment services should be developed on an incremental basis to provide assessment and treatment of men and women with a learning disability who have specific mental health needs and/or challenging behaviours. The community based assessment and treatment services will encompass behaviour support expertise that will provide outreach to individuals, families and community services and short-term intensive treatment to those within a residential facility which may be approved to treat people under mental health legislation.

Recommendation 48 As a consequence of the other mechanisms being recommended the Department of Health, Social Services and Public Safety should establish a regional plan that sets targets for the reallocation of existing resources and the securing of additional resources to enable the community services to be established.

Recommendation 49 Some people with a learning disability are at increased risk of recurrent severe challenging behaviours and/or mental illness. Health and Social Services Trusts should ensure that protocols are agreed so that a proactive approach can be taken to systematic intervention should there be signs of recurrence.

Recommendation 50 By December 2006 the Department of Health, Social Services and Public Safety should produce in partnership with service providers regional guidelines on the management of challenging behaviours within services.

OBJECTIVE 8 To ensure that men and women with a learning disability are supported to age well in their neighbourhoods.

Recommendation 51 The Department of Health, Social Services and Public Safety should review funding allocations to ensure that the projected increase in numbers of older people with a learning disability is reflected in the allocations to the learning disability programme. This shift will take cognisance of the fact that people with a learning disability may experience the effects of ageing at an earlier age.

Recommendation 52 The Department of Health, Social Services and Public Safety and Health and Social Services Boards should produce a strategic plan to address current deficiencies in services and future service provision for older people with a learning disability and their families.

Recommendation 53 Arrangements should be developed to enable people with a learning disability who have dementia to access support and expertise from mainstream dementia services. This will include mechanisms to provide a skills boost between dementia services and dedicated learning disability services.

OBJECTIVE 9 To enable people with a learning disability to have as much control as possible through developing person centred approaches in services and ensuring wider access to advocacy and Direct Payments.

Recommendation 54 By 1 January 2009 the opportunity to have a PCP should be in place for all persons with a learning disability who are in contact with HPSS agencies. From 2006 priority should be given to:

- developing Family Support Plans based on person centred principles that cross disciplines and agencies
- developing an Early Intervention Plan for children at the point of diagnosis

- ensuring that all young people with a learning disability have an effective Transitions Plan based on PCP principles in place from 14 years of age

- ensuring that all persons living with a sole family carer and/or those aged over 50 years have been offered the opportunity to have a Futures Plan agreed based on PCP principles. In addition a plan for meeting the needs of carers should be prepared. This invitation should be re-issued to family carers and the person they care for on a regular basis and no less than every 3 years.

Recommendation 55 The use of Direct Payments should be widely promoted and additional revenue monies of up to £300,000 per annum over the next 3 years ear-marked by the Department of Health, Social Services and Public Safety for the development of increased uptake of Direct Payments.

Recommendation 56 An independent advocacy service should be in place for each area serving a population of 100,000 – 120,000. A Regional Forum for People with a Learning Disability should be established with representatives drawn from local advocacy services. Both initiatives should be grant-aided through Office of the First Minister and Deputy First Minister (OFMDFM), so that they can cover all services and not just those provided by the Department of Health, Social Services and Public Safety.

Recommendation 57 A commissioning requirement of any service that includes people with a learning disability must be the evidence from providers across departments and agencies of how information will be provided in an accessible format appropriate to the needs of the individuals being supported.

Recommendation 58 Health and Social Services Boards should be required, within a regionally agreed framework, to establish mechanisms in partnership with their service providers for monitoring the degree to which Person Centred Planning is appropriately implemented and delivers on positive personal outcomes for individuals with a learning disability.

Recommendation 59 The Health and Personal Social Services Regulation and Improvement Authority should include measurement in the standards against which learning disability services are inspected of the processes used in service delivery to secure positive personal outcomes.

Recommendation 60 A commissioned programme of research and service evaluation to support the implementation of the Equal Lives Review should be established in collaboration with the Research and Development Office.

OBJECTIVE 10 **To ensure that health and social services staff are confident and competent in working with people with a learning disability.**

OBJECTIVE 11 **To ensure that staff in other settings develop their understanding and awareness of learning disability issues and the implications for their services.**

Recommendation 61 HSS Boards and Trusts should agree the role, composition, configuration and functions of Community Learning Disability Teams in light of the proposals in the Equal Lives Review by December 2006.

Recommendation 62 By April 2007 a regional workforce development strategy should be produced in partnership with employers from the independent and statutory sectors that identifies the workforce implications of the Equal Lives Review and sets out a clear strategy for addressing them.

Recommendation 63 All service providers who receive funding from the Department of Health, Social Services and Public Safety Training Support Programme should be required to evidence how people with a learning disability have been involved in the design, delivery and/or evaluation of training programmes provided on learning disability specific issues.

Recommendation 64 Service providers who receive Training Support Programme funding should be required to demonstrate that arrangements are in place to open access to the training provision to family carers, volunteers and people with a learning disability where possible.

Recommendation 65 Funding should be allocated to the Review Implementation Steering Committee for a Leadership Innovation Fund to which all agencies and professions might apply, designed to promote interagency initiatives that develop the leadership and managerial capacity in organisations to deliver on the new vision in the Equal Lives Review.

Recommendation 66 From 1 January 2007 all new Direct Support Workers in learning disability services should be required to meet the Northern Ireland Social Care Council standards on induction and foundation within the first year of appointment. It is anticipated that this will normally be evidenced by completion of assessment to LDAF standards and be subject to inspection by the Health and Personal Social Services Regulation and Improvement Authority.

Recommendation 67 All generically trained health and social services professionals (medicine, Allied Health Professionals, nursing, social work) should receive at a minimum awareness raising training on learning disability.

Recommendation 68 A publicity strategy should be developed and implemented that promotes the positive factors of working with people with a learning disability and encourages greater participation in volunteering and community service.

Recommendation 69 Department of Education, Department for Social Development and Department for Employment and Learning should develop measures to encourage awareness raising and improved training on learning disability amongst agencies that they fund to support equity of access by people with a learning disability to their provision. These measures should include the development of joint training opportunities with health and social services agencies.

OBJECTIVE 12 **To promote improved joint working across sectors and settings in order to ensure that the quality of lives of people with a learning disability are improved and that the Equal Lives values and objectives are achieved.**

Recommendation 70 An Interdepartmental Steering Committee should be established by January 2006 to promote joint working and oversee the implementation of the Equal Lives Review recommendations.

Recommendation 71 An Implementation Support Team should be established by November 2005 to support work being undertaken to implement the Equal Lives Review.

Recommendation 72 A Regional Forum for People with a Learning Disability should be established by January 2006.

Recommendation 73	Inter-Agency Task Groups should be established by April 2006 to drive change at a local level and produce local plans in accordance with the Equal Lives values and objectives.
Recommendation 74	Ring-fenced funding continues within Department of Health, Social Services and Public Safety and Department of Education and the potential is explored for extending this to other departments to underpin the implementation of the Equal Lives Review.

REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY (N. IRELAND)

Annex B

TERMS OF REFERENCE

1. To carry out an independent review of the effectiveness of current policy and service provision relating to mental health and learning disability, and of the Mental Health (Northern Ireland) Order 1986.

2. To take into account:

   - the need to recognise, preserve, promote and enhance the personal dignity of people with mental health needs or a learning disability and their carers;
   - the need to promote positive mental health in society;
   - relevant legislative and other requirements, particularly relating to human rights, discrimination and equality of opportunity;
   - evidence - based best practice developments in assessment, treatment and care regionally, nationally and internationally;
   - the need for collaborative working among all relevant stakeholders both within and outside the health and personal social services sector;
   - the need for comprehensive assessment, treatment and care for people with a mental health need or a learning disability who have offended or are at risk of offending; and
   - issues relating to incapacity.

3. To make recommendations regarding future policy, strategy, service priorities and legislation, to reflect the needs of users and carers.

EXPERT WORKING COMMITTEES

Annex C

FIRST WAVE

- Social Justice and Citizenship:

Convenor: Bill Halliday, Equality Commission for Northern Ireland

To consider relevant legislative and other requirements, particularly relating to human rights, discrimination and equality of opportunity; and how best to promote the social inclusion of people with a mental health problem or learning disability and their carers, taking account of employment, housing, education, social security, personal finance and other social issues.

- Legal Issues:

Convenor: Master Brian Hall, Office of Care and Protection

To include a review of the Mental Health (N Ireland) Order 1986; the Mental Health Commission; the Mental Health Review Tribunal; the procedures for the transfer of patients to and from N Ireland; issues relating to people who are not able to look after their own property and affairs as a result of a mental health problem or learning disability; and issues relating to people with a mental health problem or a learning disability who are in contact with the criminal justice system.

- Learning Disability:

Convenor: Siobhan Bogues, Manager, ARC (NI)

To review policy and services for children and adults with learning disability.

- Adult Mental Health:

Convenor: Professor Roy McClelland, Deputy Chair of the Review

To include consideration of primary care provision, acute services, rehabilitation and community care for adults with a mental health problem.

SECOND WAVE

- Mental Health Promotion:

Convenor: Professor Alan Ferguson, Chief Executive, NI Association for Mental Health

To include consideration of how best to promote positive mental health in society, with particular reference to the impact of the recently-published Mental Health Promotion Strategy, and how best to meet the needs of people at risk of suicide.

- **Child and Adolescent Mental Health:**

  Convenor: Moira Davren, Royal College of Nursing

  To include consideration of primary care provision, acute services, rehabilitation and community care for children and adolescents.

- **Dementia and Mental Health Issues of Older People:**

  Convenor: Nevin Ringland, Chief Executive, PRAXIS Care Group

  To include consideration of primary care provision, acute services, rehabilitation and community care for older people with dementia or a mental health problem.

- **Alcohol and Substance Misuse:**

  Convenor: Dr Diana Patterson, Shaftesbury Square Hospital

  To include consideration of the links between mental health and alcohol and substance misuse, and the provision of the most appropriate assessment, treatment and care for those involved.

- **Forensic Services:**

  Convenor: Dr Fred Browne, Chair, Northern Ireland Division, Royal College of Psychiatrists

  To consider the assessment, care and treatment of people with a categorical mental illness, severe personality disorder or who engage in dangerous or persistently challenging, aggressive behaviour, and who may be in contact with the criminal justice system.

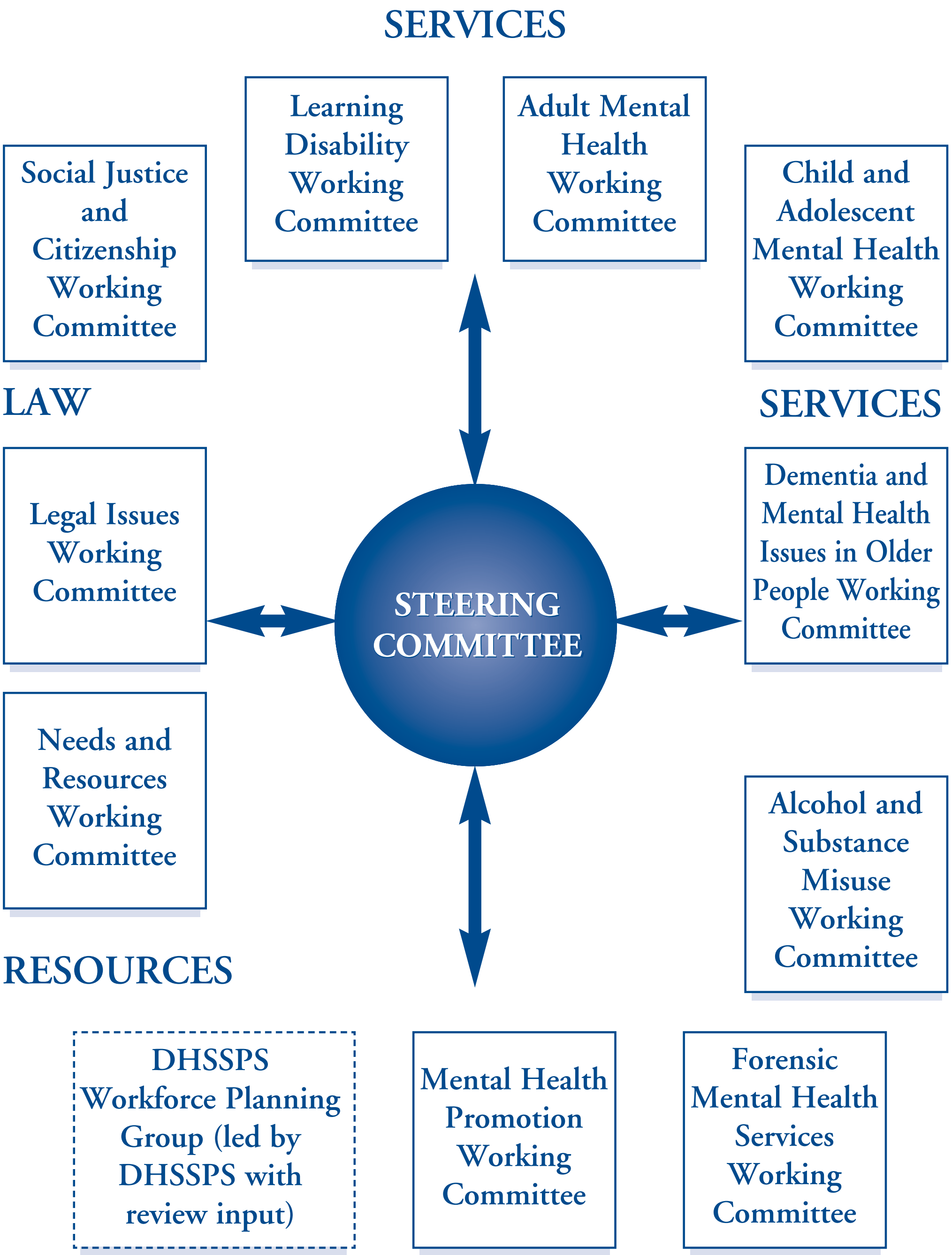
- **Needs and Resources:**

  Convenor: Glenn Houston, Chief Executive, Craigavon and Banbridge Health and Social Services Trust

  To support other working committees in assessing the financial implications of their recommendations.

THE REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY (NORTHERN IRELAND)

COMMITTEE STRUCTURE



GLOSSARY

Annex D

Allied Health Professionals	These include physiotherapists, speech and language therapists, occupational therapists, podiatrists, radiographers, and dieticians
Challenging Behaviour	When someone is behaving in a way that might cause harm to themselves or to other people. Services are challenged to find a way of managing the behaviour so the chance of harm is reduced
Citizenship	People with a learning disability are treated as equal citizens
Domiciliary Support	Support provided to a person in their own home
Empowerment	People with a learning disability are supported to take a full part in decisions affecting their lives
Expert Working Committee	A group including carers, men and women with a learning disability and staff who were asked by the Review to find out what needs to be done to make things better for people in the future
Forensic Issues	Issues for people with a learning disability who commit offences whether or not they come in contact with the criminal justice system or who are at risk of offending
Inter-agency	Links between organisations that have responsibility for either the commissioning and/or the delivery of services
Intra-agency	Subsections within the one agency working together more closely
Inter-departmental[1]	Government departments working together
Inter-disciplinary/ Inter-professional	Staff in services from different professions working together with an individual service user, or in the planning and delivery of services to groups of service users and carers. E.g. nurses, social workers, teachers, allied health professionals, clinical psychologists and psychiatrists
Inter-sectoral	Working together between the statutory sector (bodies that are directly managed by government) and the independent sector (voluntary organisations, community groups and the private sector)
Legislative	To do with the law
Mainstream	Generally available to everyone in the community

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[1] Other terms are sometimes substituted such as cross departmental or pan–agency working. These are taken to mean the same as inter as in inter-departmental

Multi- Agency Centres	A one-stop shop for children, their families and the staff who support them where staff from a range of organisations are in the one place to offer support, advice and information
Prevalence	Working out how many people in a community have a learning disability
Primary Care Services	Health and social services that are generally available directly to everyone e.g. dentist, GPs
Revenue Allocations	Money allocated for daily costs like staff salaries or rent
Sensory Impairments	A loss of sight and/or hearing
Social Inclusion	When people with a learning disability feel part of the community that they live in
Supported Employment	Helps people with a disability to get a job by giving the right help and support
Terminology	The names we use for different things
Transition	A time in people's lives when big changes are happening, like leaving school or getting old

Abbreviations

ARC	Association for Real Change
DCAL	Department of Culture, Arts and Leisure
DE	Department of Education
DEL	Department for Employment and Learning
DHSSPS	Department of Health, Social Services and Public Safety
DRD	Department for Regional Development
DSD	Department for Social Development
EHSSB	Eastern Health and Social Services Board
FE	Further Education
HPSSRIA	Health and Personal Social Services Regulation and Improvement Authority
HPSS	Health and Personal Social Services
HSS	Health and Social Services
LDAF	Learning Disability Award Framework
NHSSB	Northern Health and Social Services Board

NICVA	Northern Ireland Council for Voluntary Action
NISCC	Northern Ireland Social Care Council
NVQ	National Vocational Qualification
OFMDFM	Office of First Minister and Deputy First Minister
PCP	Person Centred Planning
PSS	Personal Social Services
RPA	Review of Public Administration
SHSSB	Southern Health and Social Services Board
SLD	Severe Learning Disability
TSP	Training Support Programme
UN	United Nations
WHSSB	Western Health and Social Services Board

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COMPOSITION OF EQUAL LIVES REVIEW WORKING GROUPS

Annex F

Learning Disability Working Committee

Andrew Bailey	PSNI
David Bamford	Chair Mental Health and Learning Disability Review
Siobhan Bogues	ARC
Maurice Devine	Down Lisburn Health and Social Services Trust
Kieran Downey	Sperrin Lakeland Trust
John Hunter	Department of Education Northern Ireland
Mary Lunny	Parent
Agnes Lunny	Positive Futures
Roy McConkey	University of Ulster at Jordanstown/ Eastern Health and Social Services Board
John McEleney	Foyle HSS Trust
Catherine McGuigan	Equal Lives Group
Joan McGuinness	Longstone Hospital
Colin McMinn	DHSSPS
Brendan Mullen	Ulster Community & Hospitals HSS Trust
Marian Nicholas	Parent
Maureen Piggot	MENCAP
Moira Scanlon	Occupational Therapist
Oliver Shanks	Psychiatrist
Eileen Sherrard	Clinical Psychologist
Tom Smith	Southern Health and Social Services Board
Miriam Somerville	North & West Belfast HSS Trust
Nigel Stratton	Homefirst Community Trust

Equal Lives Group

Orlagh	Cassidy
Joe	Coyle
Hilary	Gammon
Alan	Henry
Gerald	Maguire
John Paul	McCusker
Catherine	McGuigan
Cathy	McKillop
John	Mullan
Patrick	Hill
Nigel	Reid
Trevor	Rhodie
Nora	Smith

Advisers to Equal Lives Group

Paul	Roberts
Siobhan	Wylie
Judith	Skates (secretary)

Carers Advisory Group

Sam	Bell
Anne	Blake
Colm	Callon
Briedge	Campbell
Derek	Doherty
Sharon	Doherty
Mary	Duffin
Maureen	Gribben
Carol	Ince
Colette	Jones

Siobhan	Lappin
Mary	Lunny
Anne	Mallon
Valerie	Martin
Pat	McAlister
Teresa	McDonagh
Nuala	McGarry
Seana	McQuade
Cowan	Reid

Accommodation and Support Task Group

John Black	DHSSPS
Tony Brady	Carer
Agnes Lunny	Positive Futures
John Mc Cart	North & West Belfast HSS Trust
Roy Mc Conkey	University of Ulster at Jordanstown/ Eastern Health and Social Services Board
Colin Mc Minn	DHSSPS
Brian O' Kane	Supporting People
Tom Smith	Southern Health & Social Services Board

Ageing Issues Task Group

Kate Comiskey	Blair Lodge
Chris Conliffe	Scientist Practitioner
Peter Deazley	DHSSPS
Margaret Maybin	Training and Practice Development Team
Janet MacPherson	North & West Belfast HSS Trust
Moira Scanlon	Craigavon & Banbridge HSS Trust
Kay Trolan	Parent
Vivienne Williamson	St Luke's Hospital

Children and Young People Task Group

Margaret Black	Northern Health and Social Services Board
Oscar Donnelly	North & West Belfast HSS Trust
Pauline Ferguson	Positive Futures
Hilary Harrison	DHSSPS
Nan Hill	South & East Belfast HSS Trust
John Hunter	Department of Education Northern Ireland
Goretti Horgan	Parent
Mandy Irvine	North & West Belfast HSS Trust
Rosemary Kilpatrick	Institute of Child Care Research
Mary Lunny	Parent
Pat McAlister	Parent
Alison McCullough	South & East Belfast HSS Trust
Aidan Murray	Eastern Health and Social Services Board
Michael Palframan	Barnardos
Maureen Piggot	MENCAP

Day Opportunities Task Group

Alison Anderson	Skill Northern Ireland
Liam Burns	MENCAP
Damian Cassidy	The Appleby Trust
Kieran Downey	Sperrin Lakeland Trust
Edyth Dunlop	Northern Ireland Union for Supported Employment
Ian Hayes	Service User
Brendan Linton	MENCAP
Roy Mc Conkey	University of Ulster at Jordanstown/ Eastern Health and Social Services Board
Barry Mc Menamin	MENCAP
Colin Mc Minn	DHSSPS
Eilish Rehill	FACT
Jude O'Neill	Western Health & Social Services Board

Physical Health Task Group

Owen Barr	University of Ulster at Magee
Maurice Devine	Thompson House Hospital
Sean Donnelly	Clifton Street Surgery
Lucy Finnegan	South & East Belfast HSS Trust
Therese Kane	Albert Street Healthy Living Centre
Neil Kelly	South & East Belfast HSS Trust
John McEleney	Foyle HSS Trust
Margaret Mc Elroy	Carer
Eveline Milne	Longstone Hospital

Mental Health Task Group

Owen Barr	University of Ulster at Magee
Don Bradley	Ulster Community & Hospitals HSS Trust
Petra Corr	North & West Belfast HSS Trust
Maurice Devine	Thompson House Hospital
Ian Mc Master	DHSSPS
Joan Mc Guinness	Longstone Hospital
Brendan Mullen	Ulster Community and Hospitals HSS Trust
Marion Nicholas	Parent
Oliver Shanks	Psychiatrist
Irene Sloan	Challenge
Miriam Somerville	North & West Belfast HSS Trust

LEGISLATION IN NORTHERN IRELAND

Annex G

Most of the recent legislation in Northern 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:

Chronically Sick and Disabled Persons (NI) Act 1978

This provides for the identification of people with a disability for the purpose of providing welfare services under the Health and Personal Social Services (NI) Orders 1972. It also provides for the laying before the NI Assembly of two reports, one on the placement of people under 65 in a hospital mainly for the care of elderly people (Section 12 report) and the other on the placement of people under 65 in premises for people over that age (section 13 report).

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 Order also allows for people to be received into guardianship to ensure that the person receives the care and protection he or she needs. The Order also allows steps to be taken to manage the property and affairs of people who cannot do so for themselves.

Education and Libraries Boards (NI) Order 1986 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.

Disabled Persons (NI) Act 1989

The Chronically Sick and Disabled Persons (NI) Act 1978 was amended by the Disabled Persons (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 1989 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 (NI) 1995

This Order was made in March 1995 and most of its provisions commenced in 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 carers' 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:

- must have a physical or mental impairment
- the impairment must adversely affect the individual's ability to carry out normal daily activities
- the adverse effect must be substantial
- 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.

SELECTED DEFINITIONS OF LEARNING DISABILITY

Annex H

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 ability 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; and
- 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’)

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 and 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 areas 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".

HPSS EXPENDITURE ON LEARNING DISABILITY PROGRAMME

Annex I

By Trust 2002/03

HSS Trust	Hospital £'000	Community £'000	PSS £'000	Total £'000
Armagh & Dungannon	8375	1354	6596	16325
Causeway	150	546	4565	5261
Craigavon & Banbridge		791	5204	5995
Down Lisburn		1793	10300	12093
Foyle	2908	1313	7302	11523
Green Park	698			698
Homefirst	97	2604	15826	18527
Newry & Mourne		845	5921	6766
North & West Belfast	20734	1198	11284	33216
South & East Belfast		522	9760	10282
Sperrin Lakeland		330	6922	7252
Ulster Community and Hospitals		873	7555	8428
United		85		85
TOTAL	**32962**	**12254**	**91235**	**136451**