

Chapter 1:

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

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

The chapter is divided into six sections.

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

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

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

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

Section 5 outlines current service provision and funding sources.

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

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

Appendix 1.1: Legislation in Northern Ireland

Appendix 1.2: Terms used internationally for learning disability.

Appendix 1.3: International definitions of learning disability.

Section 1: Modern thinking about disability

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 Old conceptions that emphasised their differences and deficits have been replaced by the idea that they are people first and foremost. Likewise, beliefs about helplessness, worthlessness and exclusion have been superseded with aspirations for their 'full participation and equality' within society and efforts made to reduce their disabilities through provision of appropriate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

Rights statements

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

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

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

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

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

"Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services" (Para 26).

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

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

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

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

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

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

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

Legislation

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

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

Recent legislation largely serves two main purposes.

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

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

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

Future Legislation

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

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

Policy changes

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

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

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

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

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

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

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

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

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

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

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

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

“Legal and Civil Rights: *People with learning disabilities have the right to a decent education, to grow up to vote, to marry and have a family, and to express their opinions, with help and support to do so where necessary.*

Independence: *Promoting independence is a key aim for the Government's modernisation agenda. ... While people's individual needs will differ, the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this.*

Choice: *Like other people, people with learning disabilities want a real say in where they live, what work they should do and who looks after them. But for too many people with learning disabilities, these are currently unattainable goals. We believe that everyone should be able to make choices.*

Inclusion: *Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community.*

Policy statements from Health and Social Service Boards

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

“To work with individuals to help them achieve and maintain a valued lifestyle”

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

“To enable people with learning disabilities to live lives as normal as possible, maximising opportunities for personal development and fulfillment; and

To secure and develop a coordinated and balanced range of generic and specialised services in keeping with those needs”.

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

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

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

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

Conclusions

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

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

Section 2: Defining and assessing learning disability

Terminology

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

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

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

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

Models of disability

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

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

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

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

Appendix 1.3 documents the significant definitions of learning disabilities presently in use internationally. It quickly becomes apparent from a cursory reading that the older

definitions – and those mostly used in Northern Ireland – emphasise the personal deficits approach to disability.

Social model of disability

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

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

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

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

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

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

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

Common Features

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

Box: Four dimensions for describing disabilities

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

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

Defining Learning Disability

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

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

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

Northern Ireland Definitions

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

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

This definition or minor variants is also used in Social Security (Disability Living Allowance) Regulations 1991; Police and Criminal Evidence (NI) Order, 1989; Registered Homes Act 1984 and Regulations; Road Traffic Act, 1988¹.

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

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

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

Severe Mental Impairment: 'A state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning, and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned'.

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

Assessing for a learning disability

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

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

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

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

inherent difficulties with many such instruments, the use of a formal assessment of adaptive/social functioning should be seen as good practice. At least one assessment (preferably completed with more than one informant, and on more than one occasion) should be carried out” (p. 7).

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

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

I Intellectual abilities

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

III Participation, interactions and social roles

IV Health – physical health, mental health and aetiological factors

V Context – environmental and cultural.

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

Implementation

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

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

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

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

Why assess?

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

Service eligibility: The goal of this assessment is to limit scarce resources to those that require them. This can be wide ranging – for example is a person eligible to receive services under the learning disability programme of care from Health and Social Service Trusts - or more specific entitlements to receive Disability Living Allowance; or to require treatment from a speech and language therapist. In these instances it is

important that common assessment tools and definitions are used to be fair to everyone. They need to be reliable but not overly detailed so that they can be administered to all applicants to the service.

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

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

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

Redefining eligibility

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

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

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

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

Third, the onus is on the service to precisely define the criteria that makes a person eligible for the special service. In many ways we still live with the old idea of one learning disability service – i.e. eligibility of admission to the programme of care substituting for the institution - rather than recognising the diversity of services that are delivered within a learning disability programme of care. Hence each defined service within the overall programme of care needs to produce the criteria for admission, especially for those services where demand exceeds supply, such as the provision of respite (short-term) breaks; attendance at day centres. This recognises the reality that

everyone with a learning disability does not require every service. The assessment of the person then becomes one of whether or not they meet the criteria for entitlement. Again it is likely that these assessments will be based around functional limitations, social inclusion and supports. This approach also recognises that people's need for a service can be for on a short-term as well as a long-term basis.

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

Conclusions

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

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

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

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

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

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

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

* Health Research Board (2003)

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

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

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

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

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

Future predictions of population

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

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

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

There are some trends that may result in decreasing numbers:

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

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

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

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

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

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

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

Service settings

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

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

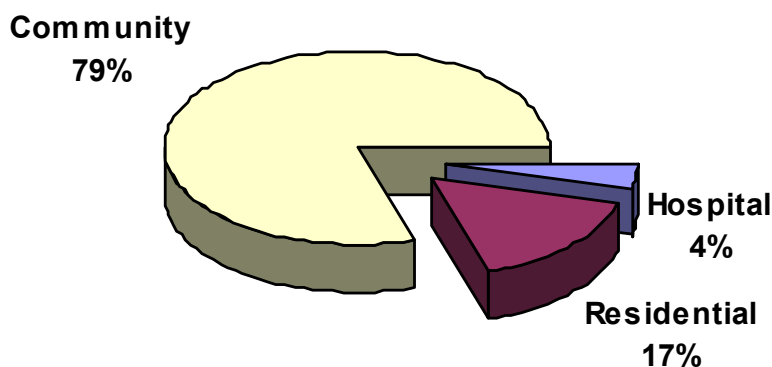


Figure 1a: The proportions of people aged 20 years and over living in different settings

Hospital: In 2003, an estimated 440-470 persons were living in hospitals and had no other address to which they could be discharged. Some were recent admissions because their previous placement had broken down but most had lived in hospital for many years with a mean length of stay of 20 years. They form the population that

requires to be resettled. Their mean age is around 50 years and two-thirds are recorded as having 'severe' rather than 'moderate' learning disabilities.

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

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

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

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

Links with social and economic deprivation

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

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

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

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

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

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

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

Conclusions

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

Section 4: The impact of the 'troubles'

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

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

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

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

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

Troubles-related impacts

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

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

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

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

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

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

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

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

Conclusions

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

Section 5: Service provision and funding

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

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

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

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

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

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

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

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

Family and home support: Domiciliary workers, home helps, provision of aids and appliances, home adaptations, fostering and adoption services; breaks with host

families; long-term adult placement schemes; respite breaks away from their usual residence settings, information and advice services, counselling services.

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

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

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

Person-centred services

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

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

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

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

However the conclusions of a systematic review of 21 studies of person-centred planning found limited evidence for their efficacy (Rowe and Rudkin, 1999). Less than half the reports in the review described the outcomes for service-users although the

qualitative data that was presented provided considerable evidence that this form of planning resulted in more person-centred plans than did professionally-lead individual programme plans. Also there was evidence of increased choices being offered to clients and desirable outcomes were achieved in the areas of social, educational and residential supports. However In the absence of suitable contrast groups, it was not possible to conclude that the planning process per se produced these outcomes.

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

Conclusions

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

Funding

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

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

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

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

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

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

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

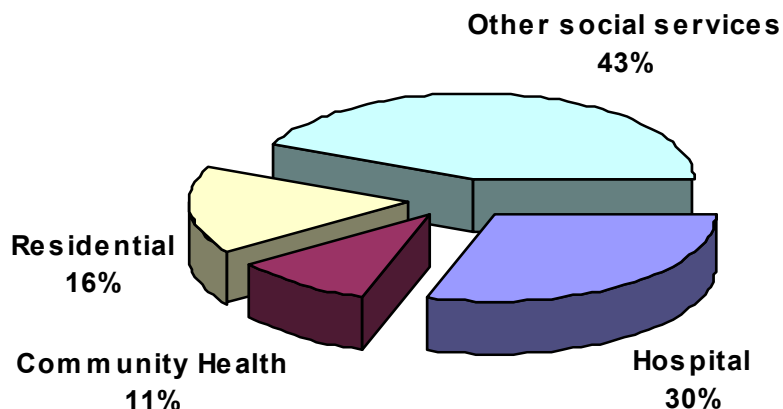


Figure 2: The proportions of monies spent in the Learning Disability Programme of Care – year end 31 March 2002 (Total £105.7 million).

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

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

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

Other funding sources

It is difficult to obtain precise figures for the amount of monies expended by other Government departments on people with a learning disability³. This will include:

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

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

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

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

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

Variation in costs

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

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

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

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

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

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

Conclusions

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

Section 6: Inequalities and people with a learning disability

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

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

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

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

Potential inequalities

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

Family Carers

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

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

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

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

Siblings of the severely learning disabled children may also face inequalities with many having less contact with friends and increased levels of anxiety compared to other children (Coleby, 1995). In addition siblings are expected to contribute to caring and in

some cases they may take on a major role in this, which has the potential to limit their life experiences and opportunities.

Children⁴

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

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

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

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

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

Physical Health

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

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

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

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

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

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

Older people

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

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

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

People who challenge

The stigma, which leads to people with a learning disability being segregated in many areas of life, is exaggerated when they have additional challenging behaviours⁵.

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

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

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

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

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

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

Conclusions

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

Human Rights and Discriminatory practices

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

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

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

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

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

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

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

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

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

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

Addressing Human Rights Issues

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

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

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

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

There are promising indications that Government is addressing these issues.

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

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

These are useful government initiatives and they do aim to address need and inequality across all society (a virtuous aim in itself) but past experience has shown that there is a

need for persistent and frequent lobbying of government departments with respect to the needs of learning disabled people otherwise the concept of learning disability as a *Cinderella Service* will perpetuate.

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

Conclusions

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

Possible Inequities in service provision

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

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

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

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

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

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

- Northern Ireland has the highest proportion of people resident in long-stay hospitals and also has the single largest hospital in these islands. (15 beds per 1 million population in England and Wales; 163 beds per 1 million in Scotland and 264 beds

per 1 million in Northern Ireland). All long-stay hospitals are due to close in England in 2004 and in Scotland by 2005.

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

Conclusions

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

Future Prospects

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

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

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

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Appendix 1.1: Legislation in Northern Ireland

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

The Mental Health (NI) Order (1986)

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

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

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

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

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

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

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

The Disabled Persons (NI) Act 1989 also gives disabled people rights to representation, to assessment of their needs, and to information and counselling. The statutory provisions relating to representation are provided in Sections 1 and 2 of the 1988 Act and intended to give the same rights to disabled people in Northern Ireland as that given in Great Britain by the Disabled Persons (Services, Consultation, and Representation) Act 1986. For example, Section 2 requires Boards or Trusts to make

arrangements for social services to meet the needs of disabled people, including practical assistance in the home, transport arrangements to and from home, home adaptations, holidays and help obtaining a telephone. However, ten years on, these two sections have not yet been implemented in N. Ireland.

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

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

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

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

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

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

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

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

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

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

Northern Ireland Act 1998

Section 75 of the Northern Ireland Act 1998 states:

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

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

Between men and women generally;

Between persons with a disability* and persons without; and

Between persons with dependants and persons without”.

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

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

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

Other UK legislation:

Three further pieces of legislation also have implication for services

Carers Recognition and Service Act (1995) :

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

Community Care Direct Payments Act (1996)

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

Disability Discrimination Act (1996)

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

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

Under the DDA disabled people are defined as follows:

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

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

Appendix 1.2: International Terminology

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

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

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

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

Alternative terms

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

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

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

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

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

Intellectual Disability The World Health Organisation has adopted this term; making an important distinction between handicaps which tend to be acquired over time and disabilities which are usually present from birth and which may or may not become a

handicap. This term is now being used increasingly internationally and especially by countries in the developing world as they begin to establish specialist services for these clients.

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

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

Appendix 1.3: Selected definitions of 'learning disability'.

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

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

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

Northern Ireland

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

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

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

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

Great Britain.

The Scottish Review of Learning Disability Services (Scottish Executive, 2001) considered it important for any definition to give an appropriate and meaningful description of the services 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 area of major life activity: self-care, receptive and expressive communication, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency. People with intellectual disabilities generally need a combination of special, interdisciplinary or generic services, individualized support, and other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated”.

United States of America

DSM-IV Diagnostic and Statistical Manual of Mental Disorders

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

- (a) significantly sub-average intellectual functioning: an IQ of approximately 70 or below on an individually measured administered IQ Test.*
- (b) Concurrent deficits or impairments in present adaptive functioning (i.e. the person's effectiveness in meeting the standards expected of his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home-living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.*
- (c) The onset is before age 18 years.*

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

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

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

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

