

ANNEX VIII: IRELAND

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Introduction

Definitions and Terminology

There is no broad, over-arching definition of intellectual disability in Ireland. Several definitions of disability exist that are policy driven and specific to the legislative area in question i.e. employment, education, equality. The most recent disability-related act, The Disability Act 2005 asserts, “disability, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment” (Section 2).

Legislative definitions of disability are clearly based on a medical/clinical view of disability in that they provide a list of medical conditions from which intellectual disability may result. Despite the wording of these definitions, there is an awareness that legislation must be interpreted in a social context. In the past, intellectual impairment has been conceptualised as something that must be ‘cared for’ in a charitable sense, but there has been a move to change this outlook and implement more inclusive policy to facilitate this attitudinal change. Therefore, the State adheres to a rights based, social model of intellectual disability in implementing its various policies (McDonnell, 2003).

In practice several terms are used interchangeably to describe intellectual impairment in the Irish context. The term ‘intellectual disability’, a term that is recognised internationally, is typically used in research settings and has also been adopted as the standard by certain government bodies (Department of Health and Children) to describe intellectual impairment. It has also become the standard description for intellectual impairment in legal areas. The Mental Health Act (2001), for example, includes ‘significant intellectual disability’ as one of the grounds of ‘mental disorder’ and defines it as “a state of arrested or incomplete development of mind of a person which includes significant impairment of intelligence and social functioning and abnormally aggressive or seriously irresponsible conduct on the part of the person” (Section 3).

In recent years the term ‘learning disability’ has begun to replace the term ‘mental handicap’, but in an international setting is a term typically used when referring to specific difficulties such as dyslexia. The terms ‘intellectual disability’ and ‘learning disability’ are often used interchangeably. ‘Learning disability’ is also commonly used in educational settings where a child requiring special educational needs, whether they be as a result of an intellectual disability or other type of disability, would be considered learning disabled. The British Psychological Society (BPS) guidelines, which would be widely acknowledged in Ireland, define learning disability as being an impairment in intellectual disability (two standard deviations below the mean on a standardised test of intelligence, which would typically be an IQ score less than 70) accompanied by impaired adaptive/social functioning that is apparent before the onset of adulthood (BPS, 2001).

The term ‘mental handicap’, although considered an outdated term because of its negative connotations, is still used by Irish people and by some disability-related organisations and service providers. Inclusion Ireland -The National Association for People with an Intellectual Disability (NAMHI), a voluntary organisation promoting the rights of people with disabilities, define mental handicap as a “greater than average difficulty in learning. This results in a delayed or incomplete development of a person’s mind, and presents difficulties in the person’s ability to adapt to the cultural demands of society”. The term ‘mental handicap’ is a broad term that is used to describe people with mild impairments to those with profound intellectual disabilities. The American term ‘mental retardation’ is synonymous but not in use in Ireland.

Legal Status

In Ireland, people with intellectual disabilities have the same civil rights as any other citizen of the State. Bunreacht na hEireann (1937), the Irish Constitution, lays down the fundamental rights of each citizen and creates the basis of the Irish legal system, thus informing the way in which legislation is interpreted. The constitution does not refer to people with disabilities or the issue of intellectual disability, but Article 40 of the enactment explains the basis for equality as an Irish citizen. It provides rather a narrow definition of equality in that it explains what constitutes discrimination or 'injustice' by the state, but does not fully explain the bases for equality in Irish society (Quinlivan, 2004). Several enactments have been passed since the drafting of the constitution that have built on this framework in order to establish legal rights for people with intellectual disabilities in Ireland.

The 1996 report by the Commission on the Status of People with Disabilities heralded a change in the status of people with disabilities in Ireland, by initiating reform to a rights-based model of service provision based in legislation. Ireland was one of the first countries to establish a commission of this kind. Subsequent legislation has combined articles on anti-discrimination and the provision of reasonable accommodations with measures designed to positively promote equality in Irish society. The Equal Status Act (2000) and The Disability Act (2005) are the two main rights-based disability enactments in the Republic of Ireland. The Equal Status Act (2000) was the first act to legislate against discrimination outside of the area of employment (Quinlivan, 2004). Disability was one of the nine grounds that the act prohibited discrimination of, and so it is considered an offence to do so. The Equality Act (2004) made further amendments to employment law and the law on access to goods and services by widening the definition of discrimination and by further obligating service providers and employers to provide reasonable accommodations for people with disabilities, short of it being a 'disproportionate burden'. The idea of disproportionate burden was included as it was deemed unconstitutional to pass an act that compromised the property rights of the individual.

In reality disproportionate burden only applies to a small number of cases, and an employer must undergo rigorous testing to qualify for such an exception. The employer is assessed using seven factors in order to determine whether he/she is burdened disproportionately.

Prior to the disability and equality acts, several pieces of legislation were passed that were domain specific. The Education Act (1998) was passed in order to mainstream the education of children with disabilities and to ensure equality and transparency in school access policies. It presented a framework that would allow students with disabilities 'maximum accessibility' to schools, which would also force schools to account for their individual procedures and have written policies that were compliant with the new law (Quinlivan, 2004). The act also contained policy provisions for special education within these school settings. In 2004 The Education for Persons with Special Educational Needs Act was also passed, which refined the law regarding children under the age of 18 with special educational needs. In Ireland, all people under the age of 18 have a right to a minimum level of education. Children who have special needs in education have a right to free primary education up to this age. This act proposed that every child with a special educational need should have an individual Education Plan. This system is in the process of being developed by the National Council for Special Education (NCSE), to be implemented in the near future (www.oasis.ie).

The Disability Act (2005) was recently passed following enormous contention and debate. This act constitutes part of the National Disability Strategy, a program of measures by the Irish government that aim to promote the equal participation of people with disabilities in society. This act was designed to provide specific services for people with disabilities and to mainstream access to public services and places. It also allows for the provision of assessments of health and educational needs for people with disabilities. However, the Disability Act has many critics, not least because it failed to meet an immediate need for service provision and does not offer a definitive right to having the needs identified by a health or education assessment met. The time scale for certain initiatives underlined in the act has come under scrutiny. For example,

compliance with regulations for the access of people with disabilities to public buildings need only be fulfilled by 2015. Nevertheless, the Disability Act (2005) is an important milestone as it has put procedures and rights regarding assessments and access on the statute book that were previously non-existent in Irish law.

The law regarding access to health services is currently quite complex (Relate, April 2005). The Health Acts passed in 1947 and 1953 have been amended significantly since their entry into the statute book, the most recent amendment being in 2005. Initially, these acts were concerned with building the foundations of the Department of Health, now called the Department of Health and Children. The entitlements and eligibilities listed in these acts are ever changing. The most obvious one is the right of every Irish citizen to in-patient services (Section 51 of the 1970 Health Act). However, over the years it has become evident that some of the provisions in the act may not be accommodated by the relevant health service area, and the Ombudsman has strenuously objected to the lack of clarity in the act (Office of the Ombudsman, Presentation to the Joint Committee on Health and Children, 21 June 2001 – Nursing Home Subventions, An Investigation by the Ombudsman regarding payment of Nursing Home Subventions by Health Boards). The Department of Health and Children have argued that the Act clearly identifies between “eligibility” and “entitlement”, which therefore does not obligate them to make provisions in certain circumstances. The issues that have been identified by the Ombudsman have been mainly relating to whether individuals with medical cards are entitled to free long-stay care. This evidently has the largest impact on the lives of those in the ageing population, and of course for people with intellectual disabilities who need long-term care.

Consent

There are no clear guidelines as regards consent procedures and decision-making for people with intellectual disabilities in Ireland. The law recognises the right of every adult to make decisions about their own lives, but if the ability to do this is absent there is no definite system of recourse for making a decision for the person or helping the person make a decision about their health or welfare (NAMHI, 2003). Short of the person being made a Ward of Court where all decision-making about your person and your property is assumed by others, there is no system of assessment in place to determine the capability to make decisions. In reality, relatives and service providers are often left to make decisions that may or may not be in the best interests of the person with the intellectual disability. In the Ward of Court system, someone like a relative or long-term carer (usually the committee) would make day to day decisions for the individual but important decisions impacting on the person or their property would be decided by the President of the High Court (www.comhairle.ie, accessed April 2006). Proposals have been put forward to abolish the Ward of Court system and introduce a law on legal capacity and decision-making to replace it (NAMHI, 2003).

NAMHI’s booklet, especially aimed at carers and parents entitled ‘Who Decides and How? People with Intellectual Disabilities – Legal Capacity and Decision Making’ (2003) pinpoints three main areas where problems may arise in terms of consent – management of everyday life, money and property; sexual relationships; and medical treatment. In Ireland any person over 16 can by law make their own decisions regarding medical treatment. From this age, there is no provision for anyone else to make an informed decision about medical care for the person with the intellectual disability. Although designed to protect the rights of the person with the disability, this can give rise to situations where the person may be left without the treatment, advice or service they need because their carers are not legally equipped to make decisions for them (NAMHI, 2003). Although it is generally considered that 18 years of age is the age of adult maturity, the individual is technically an adult at 17 in most domains. This is the age of sexual consent and also the age at which a person may be arrested and detained in police custody as an adult.

There is only one situation where the rights of the person may be revoked, and this is under the auspices of the Mental Health Act (2001) where, if a person with a ‘significant intellectual

disability' demonstrates a level of 'mental disorder' that is harmful to themselves or others, they may be taken into care. According to this act, the person is considered a child until the age of 18 unless they have been or are married.

Prevalence

As yet, there are no comprehensive official statistics on the prevalence of intellectual disability in the Republic of Ireland. The Central Statistics Office (CSO), the government organisation concerned with conducting the national census every four years, conducted the latest census of population in April 2006, the results of which have not been collated as yet. The 2002 census was the first official survey to ask about disability, using questions derived from the US census. It categorised people with disabilities into 6 functional categories – blindness, deafness or severe impairment; a condition that substantially limits one or more basic physical activities; difficulty in learning, remembering or concentrating; difficulty in dressing, bathing or getting around the home; difficulty in going outside the home alone; and difficulty in working at a job or business. Clearly, this did not allow for valid figures regarding intellectual disability to be delineated.

Figures published in relation to social welfare payments are even less specific, indicating that nearly 73,000 people claimed Disability Allowance (a long-term disability payment) in 2004. Of course, there is currently no way of distinguishing between those claimants that do and do not have an intellectual disability.

The upcoming census will ask directly whether or not the individual has a learning or intellectual disability as a long-lasting condition. In September 2006 the National Disability Survey (NDS) will also be conducted, which will build a more detailed picture of equality and social inclusion for people with disabilities in Ireland. This post-censal survey, also carried out by the CSO, has used the International Classification of Functioning, Disability and Health (ICF) in the construction of its survey instrument, which has already been piloted. This exercise will no doubt provide very valuable information on the health and well-being of people with intellectual disabilities in Ireland, information which will be comparable with that of other countries.

There is also information on the number of people with an intellectual disability using services and awaiting service provision in Ireland. Data on the prevalence of intellectual disability is made available each year by the National Intellectual Disabilities Database (NIDD), a service commissioned by The Department of Health and Children and managed by the Health Research Board (HRB). Details about the specific types of services availed of by people with intellectual disabilities are recorded on the National Intellectual Disability Database (NIDD), a database of service users and an assessment of need for specialised health, educational and employment services. Each year, the NIDD sends a report to each HSE area in order to plan for future services for people with intellectual disabilities.

The NIDD provides information on demographics, current service use and future service needs of people with disabilities in Ireland in order to inform on policy and planning at a local and national level. In 2005, there were 24,917 (prevalence rate of 6.36 per 1000) people with an intellectual disability registered with the NIDD. The prevalence rate was slightly higher for males compared to females (7.17 : 5.56). The prevalence rate for mild intellectual disability was 2.16 per 1000, and for moderate, severe and profound disability was 3.72 per 1000. These figures, however, are not considered to be representative of the level of intellectual disability in Ireland for several reasons. Firstly, the NIDD is a voluntary database which people with disabilities are not obligated to be part of. Also, those in the youngest age group, the pre-school group, may not be service users as a) it has been noted that some parents are unwilling to disclose information about their child's disability or b) they have not yet been diagnosed as having an intellectual disability. In the adult groups, it is also probable that the rate for mild intellectual disability is an under-estimation of the true prevalence, as many individuals may not be current service users or may not be considered to have a requirement for services in the future (Barron and Mulvaney, 2005).

To illustrate this, it is interesting to compare the NIDD figures with extrapolated data. By applying prevalence rates derived from British data (OPCS surveys of disability) to Irish census figures (2002), the National Disability Authority has estimated that there are approximately 93,000 people in the Irish population with disabilities in intellectual functioning, a figure way above that recorded by the NIDD (NDA, 2006).

As yet, there is no published material on the prevalence of intellectual disability in Ireland although at least one study (McConkey, Mulvaney and Barron, 2006) has endeavoured to estimate the number of service users with intellectual disabilities on the island of Ireland. The above authors used the NIDD (Mulvaney and Barron, 2003) and sources from Northern Ireland (that identified those over 20 with a learning disability) to obtain an overall prevalence rate of 6.34 per 1000 individuals. McConkey et al (2006) have noted that the prevalence rate is slightly higher in Ireland than in neighbouring countries, but that this may not be a 'true' estimation of the prevalence of intellectual disability on the island of Ireland. They observe that the above rate includes, at least, a true representation of those aged 20-34 with severe intellectual disabilities, people who have been service users since childhood.

Several other surveys have used representative samples to obtain prevalence rates for disability in Ireland – The Living in Ireland Survey, 2001 (Gannon and Nolan, 2004), the Quarterly National Household Survey (CSA, 2002, 2004), the National Health and Lifestyles Survey, 2002 (Department of Health and Children, 2003) and the European Social Survey, 2002 (ESS, 2002). Most of these surveys have asked questions related to long-term ill health, disability, and functional limitation in some instances, and so have obtained quite elevated prevalence rates for disability.

For example, The Living in Ireland Survey obtained a rate of 21.6% in respect of disability in their representative sample of 9131 people (Gannon and Nolan, 2004). Respondents were also asked to describe the nature of their illness or disability, and responses were coded into 22 separate categories according to the World Health Organisations International Classification of Diseases framework (Gannon and Nolan, 2004). It was found that 2.1% of respondents with an illness or a disability had an intellectual disability. The only other survey to distinguish intellectual disability from other types of disability was a phone survey by the National Disability Authority (tns-mrbi, 2004), which found that 14% of a representative sample of 500 respondents with a disability had an intellectual disability.

Service Provision

Like many European countries, Ireland has gone through a process of deinstitutionalisation. Although a proportion of people with intellectual disabilities still reside in fulltime care in psychiatric institutions, this number has been significantly reduced and that trend is to continue. There are specialist residential services for people with intellectual disabilities throughout the country, some which are religious, charitable organisations, and some whom are statutory agencies. These agencies provide either residential or independent living services to people with intellectual disabilities, or a combination of both. These types of services usually work alongside the Department of Health and Children, the HSE and other voluntary agencies in order to provide a more comprehensive level of care. Most voluntary organisations in Ireland, whether religious, charitable or statutory, are contracted by the HSE to deliver certain services. There are also certain services that are delivered directly by the HSE.

The NIDD Committee Annual Report contains information on service use and demand for each of the 10 HSE areas, and can so detect regional changes and differences in the services used and needed. In 2005, 24,078 people with intellectual disabilities were receiving services and 516 were registered on the database but were not in receipt of services. The NIDD collects information from a range of service providers, from small agencies or special schools with very few clients to

large service providers with over 1000 clients at any one time. In 2005, 458 such organisations forwarded information on their clients to the NIDD. Below is a breakdown of the type of services utilised.

Table 1: Summary of Residential Status, 2005

National Intellectual Disability Database Committee Annual Report, 2005 (p.36).

	n	%
Attending services on a day basis	15,976	64.1
Receiving 5 or 7 day residential services	7677	30.8
Resident in a psychiatric hospital	396	1.6
Receiving residential support services only	29	0.1
Receiving no service	323	1.3
No identified service requirements	516	2.1
Total	24,917	100%

Most people with intellectual disabilities tend to live in a home setting (15,827), either with both parents or with a sibling, and approximately 800 people in Ireland live in an independent setting. There are nearly 7000 people in residential centres and community group homes around the country and approximately 1200 in other types of full-time care settings i.e. nursing homes, mental health community residences, psychiatric hospitals, intensive placements. The most popular choice for residential care in the last year was community group homes, coupled with a downward trend in the popularity of residential centres. This marks a definite trend towards community living that has been evident since the start of the database. The majority of those in full-time residential settings have a moderate, severe or profound intellectual disability.

Comparatively, the level of people in residential care in Ireland is significantly higher than in Northern Ireland (McConkey, Mulvaney and Barron, 2006). One reason that has been put forward for this is the provision of 5-day residential places in the Republic of Ireland. However, even when the numbers in these short-term residential places are accounted for, there is still a higher rate of residential care in the south of Ireland than in Northern Ireland. Despite this, however, the rate of residential care in Ireland is still low compared to that of other European countries.

Despite the developing picture of service provision for people with intellectual disabilities in Ireland, there is still substantial demand for the services currently available. Between the years 2000 and 2005, a significant investment has been put into developing services for people with intellectual disabilities. These initiatives are in a sense ‘playing catch-up’ with a demand that has been evident for years and, due to population growth, is ever increasing. The NIDD state that “while a further multi-annual funding package has been put in place for the period 2006-2009, this is insufficient to address all of the service demands identified....In the medium term, it is expected that the increased demand for intellectual disability services will continue”(p.91).

In the past, children with intellectual disabilities were typically educated in a segregated manner and placed in special schools. Although special schools are still an option for parents, there has been a definite shift towards an integrated system, and mainstreaming children with disabilities has become a priority. Consequently special schools have become less popular for children with mild and specific learning disabilities. By the academic year 2002-2003 three quarters of children with disabilities being educated at primary level were in ordinary schools, and two thirds of those children were taking special classes (NDA – How far towards equality, 2005). There are two main options for parents to choose from within the mainstream system - to sit in normal classes and be assigned a learning support or resource teacher, or to attend special classes in these mainstream schools. There are also certain exemptions for students depending on their type of disability, for example the child may not have to study the Irish language, usually a compulsory subject.

Below is a table giving an indication of the general services and placements of children with intellectual disabilities in education. Approximately 8,000 children in Ireland availed of day services in 2005.

Table 2: Summary of Educational Services in 2005

National Intellectual Disability Database Committee Annual Report, 2005 (p.44).

Type of Program	Residents	Day Attenders	Total
Early intervention team	5	493	498
Mainstream pre-school	0	239	239
Special pre-school for intellectual disability	0	562	562
Child education and development centre	34	263	299
Mainstream school	4	949	953
Resource/Visiting teacher	2	315	317
Special class – primary level	9	523	532
Special class – secondary level	7	208	215
Special school	220	4102	4322

Responsibility for providing education lies with the Department of Education and Science. However, many of the educational services provided for children with intellectual disabilities fall under the auspices of health and social care provision, therefore it is very hard in some cases to clearly delineate between the two types of services. Prime examples of services that could be described as both health-related and education-related are speech and language therapy, occupational therapy and certain types of psychological services. Psychological services for students with learning impairments are provided by the HSE and by the National Educational Psychological Service, an agency in the Department of Education and Science.

Income and Benefits

It should be noted that there is no specific policy of income support for people with intellectual disabilities in Ireland. The Department of Health and Children and the HSE provide several benefits that may apply to a person with an intellectual disability. There are several places where a person with an intellectual disability, or their carer, may find information on their entitlements. Comhairle, a national support, information and advocacy organisation, publishes an up-to-date guide to entitlements aimed specifically at people with disabilities. Many of the voluntary agencies also provide literature and information on their websites.

As explained by Comhairle's booklet of entitlements, social welfare payments fall into the categories of social insurance payments (i.e. work dependent payments) and means tested payments, for those whose income falls below a certain level. Disability benefit is a work-dependent, payment provided for people who are unable to work due to illness. It is usually a short-term payment, but under exceptional circumstances may be provided for longer durations. Means tested payments such as Disability allowance are more likely to be claimed by a person with an intellectual disability. Previously called Disabled Persons Maintenance Allowance (DPMA), disability allowance is designed for people who have a long-term disability and unable to undertake work because of their disability. In January 2006 this payment maximum was 165.80 euro a week. Although this allowance does not apply to people in full-time residential care, they may qualify for a special weekly payment of 35 euro. A person with a disability may be employed in rehabilitative employment and be earning up to 120 without other means-tested payments being affected. From June 2006, if you are earning above this cut-off, a tapered withdrawal rate will be put into effect.

The HSE also provide certain payments that may apply to a person with an intellectual disability, namely Domiciliary Care Allowance and Rehabilitation Training Allowance. Domiciliary allowance is given to parents of children under 16 years with a severe disability. Eligibility for this allowance is based on the amount of extra care and attention that the parent must give rather than the type of disability, and the means test applies to the means of the child and not the carer or parent. The monthly allowance is currently at 225.20 euro. This is by no means the full extent of possible benefits that a person with an intellectual disability can claim, there are several more related to sickness and physical incapacity that may apply. However, the benefits mentioned are considered to be the most applicable to a person with an intellectual disability.

Currently there is a move towards mainstreaming people with intellectual disabilities into open employment rather than them working in sheltered positions. However, this is a slow process that requires a significant change in Irish attitudes. The HSE provides trainees in sheltered workshops with an allowance of 31.80 a week that, in most cases is supplementary to their disability allowance. It also has the responsibility of providing rehabilitative training and sheltered work to people with disabilities in Ireland, a significant proportion of which are for people with intellectual disabilities. The training and placements are facilitated through individual organisations that are contracted by the HSE. However, funding is only available for a fixed number of rehabilitation places. After completion of their course, a majority of these people will transfer to sheltered employment that, more often than not, is linked to the institution that the training was undertaken in (NDA – How far towards equality, 2005). Below is a summary of employment services utilised by people with intellectual disabilities in 2005.

Table 3: Summary of Employment Status, 2005

National Intellectual Disability Database Committee Annual Report, 2005 (p.44).

Type of Program	Residents	Day Attenders	Total
Sheltered work centre including long-term training schemes	1966	2519	4485
Sheltered employment centre	17	113	130
Enclave within open employment	5	18	23
Supported employment	143	814	957
Open employment	25	142	167

The demand for supported employment opportunities is high, with over 1000 people looking for opportunities who are currently in sheltered work or rehabilitative training (NIDD, 2005). There are also a large number of people awaiting alternative placements or enhancements to their current placements in the near future. These figures, however, clearly underestimate the degree to which certain services are utilised, and the demand for such services. The NIDD data can only ever reflect levels of participation in its own database, and because of this may not include many individuals with mild intellectual disability.

There is much crossover in the provision of employment-related services to people with disabilities in Ireland. Many disability-related organisations provide some form of training or facilitation, which falls under the auspices of either the HSE or FAS, or both. FAS, a national agency providing vocational training, career advice and placements is the main provider of specialised training to people with intellectual disabilities. It operates with the view that the training provided is to facilitate integration into a normal working environment. They provide a range of services to people with intellectual disabilities and to prospective employers that include work adaptation grants, wage subsidies, employee retention grants, supported employment and disability awareness training.

Historical Context of Health Service Provision

The association between disability and ill-health can be traced back at least as far as the Poor Relief Acts of 1838 and 1851. These acts aimed to provide accommodation in workhouses for those within a certain social class that were sick and destitute. Inevitably, many people with intellectual disabilities ended up in this system either because they were one of many who were unable to provide for themselves, or because a family member has placed them there. Consequently, a link between health and social services was fostered and, though the system has developed considerably over the years, this link is still evident in the current organisational and service provision structure.

However, it has been debated whether a system that includes services for people with disabilities with other non-disability, means tested benefits is a fair one (Quin, 2003). Furthermore, in the past certain services may have been included under the auspices of health that would now be considered inappropriate or at least impractical. This lack of organisational specialisation for people with disabilities has only been made possible by the fact that there has been such a large contribution from the voluntary sector in subsidising government initiatives over the years. It is true to say that service provision would not have developed in Ireland to the degree it has done without the significant contribution of voluntary bodies. In the past it was voluntary agencies that led the way in offering certain health and social care services (physiotherapy, occupational therapy, speech therapy, social workers etc), a situation that compelled the health boards to take a vested interest in providing such services (Quin, 2003). The picture of cooperation has developed over the years, and there is now a grant system in place whereby the HSE contracts voluntary organisations in order to provide certain residential, community and rehabilitative services. Disability Service Managers are appointed to each of the HSE areas in order to coordinate efforts and identify any gaps or overlaps that may exist in the service provision picture (www.oasis.ie).

Voluntary agencies have also been at the forefront of putting pressure on the government and making them accountable for their policies or lack thereof. There are several organisations whose sole purpose has been to further the drive towards equal rights for people with disabilities. Many of the more specific voluntary organisations, that are organised for people suffering from certain developmental disorders such as autism or downs syndrome, would have an emphasis on providing support for their members. They would also champion the rights of people with disabilities. There are also several umbrella organisations that aim to coordinate and refine the goals of these differing organisations. For example, the National Federation of Voluntary Bodies was set up in order to coordinate the efforts of various organisations providing services to people with intellectual disabilities.

Since the creation of specialist services for people with disabilities, health services have been organised in terms of distinct types of impairments i.e. people with intellectual disabilities, people with physical and sensory disabilities and people with mental health difficulties (NDA, Ageing and Disability: A discussion paper, February 2006). This categorisation is still apparent in the way that health services are structured, funded and assessed in Ireland. Another theme that has not been elaborated on in this brief discussion has been the role of psychiatric institutions in Ireland. Ireland has undergone a period of de-institutionalisation that continues to this day, a similar process perhaps to that in other European countries. The transition has been a gradual one, that has been marked by the development in community care and services, and by the ever-decreasing numbers of people with intellectual disabilities still in psychiatric institutions. There are currently less than 400 people with intellectual disabilities in psychiatric hospitals, and this number is set to be reduced even further with the creation of mental health community residences (NIDD, 2005).

Policy Framework and its Development

In 1996 the Commission on the Status of People with Disabilities published a milestone report that presented a status report on the lives of people with disabilities in Ireland and their families, as well as key recommendations for future service planning. The report was the culmination of 3

years of a consultation process completed by the Commission in the area of economic, social and cultural equality. Although much has changed in the intervening period since the report was published, it is important to note its contribution to the outlook on health and related issues that have since been adopted. The report stated that “people with disabilities, parents and carers have serious concerns as to the quality of some existing services, and about the lack of some fundamental services” (A Strategy for Equality Report of the Commission on the Status of People with Disabilities, 1996 – p. 161). In line with the 402 recommendations made in this report, there have been legislative developments to accommodate mainstreaming and better accountability in many areas, including the areas of health and social care.

Subsequently, other research and recommendations have been published by key organisations. Several organisations have been at the forefront of developing the health sector in Ireland and these include the Department of Health and Children, the Health Service Executive (HSE) areas, the Equality Authority, Comhairle, the Department of Justice, Equality and Law Reform, the Department of Social and Family Affairs, the National Disability Authority (NDA) and various voluntary and advocacy organisations working alongside government based endeavours.

In 2001 ‘Quality and Fairness: A Health System for You’ was published by the Department of Health and Children. This report set out a National Health Strategy, a plan to develop health and social care services over a period of years. It is still the blueprint for changes within the health system in Ireland today. The report endeavoured to reform the health service and provide more a more equitable, people centred service, to improve the quality of this service and to have more accountability in providing a better health service (NDA, 2003). The Strategy also had a number of recommendations that would impact on the lives of people with disabilities. For example, the creation of Health Impact Strategy, a committee delegated to address inequalities in health including those experienced by people with disabilities (NDA, 2003). This Strategy was one of several initiated by the government with a social model of service provision at its core.

The government launched its National Disability Strategy in 2004. This strategy included the newly enacted Disability Act (2005), the Comhairle (Amendment) Act (2004) as well as specific plans for service development across six government departments. A significant proportion of the funding allocated (a total of 900 million euro) will be used for specific health services such as extra residential care, respite care, and day care places, home supports, personal assistance and mental health facilities in the local community (Equality and Rights – www.Comhairle.ie).

Another important step in this process has been the creation of the National Disability Authority (NDA) after The National Disability Authority Act in 1999. The NDA’s main purpose is to develop and coordinate policy in the area of disabilities in tandem with the Minister for Justice and Law Reform. The NDA have a special advisory role in aiding in the interpretation and implementation of relevant laws, and are therefore central in the development of services in Ireland. They have a key role in assessing and monitoring the progress of services for people with disabilities in Ireland. They were also key in adopting a social model, as the NDA Act (1999) makes clear in its definition of disability as “a substantial restriction in the capacity of a person to participate in economic, social or cultural life on account of an enduring physical, sensory, learning, mental health or emotional impairment” (Section 2). One of the issues highlighted by the organisation over the last 10 years has been the lack of coordination and lack of information regarding services for people with disabilities, all underpinned by an inadequate assessment of needs. Since its creation the NDA has aimed to implement change by interpreting legislation within this framework.

The NDA have stated that health is a main priority for them. In 2001 they wrote a report for the Minister of Health and Children (Submission to the Minister of Health and Children on Health Strategy, 2001), outlining the NDA’s mandate in improving the health and health services of people with disabilities and mechanisms of accountability in the system. The NDA use the World Health Organisations definition of health – “To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realise aspirations, to

satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasising social and personal resources, as well as physical capacities” (WHO, 1998). This definition, part of WHO’s international classification of health (ICF), has informed policy and practice at a national level, and the NDA have published a series of key documents that outline inequalities and provide recommendations for the health sector.

Towards Best Practice in the Provision of Health Services for People with Disabilities in Ireland (2003).

Review of Access to Mental Health Services for People with Intellectual Disabilities (2003)

Submission to the Review of the National Anti-Poverty Strategy on Health (2001)

Submission to the Minister of Health and Children on Health Strategy (2001).

Oral Health and Disability: The way forward (March, 2005).

Submission to the Department of Health and Children on the Strategic Review of Disability Services (Sept, 2005).

Submission to the National Steering Committee on the Development of a Men’s Health Policy (January, 2006).

As well as policies relating directly to the health of people with disabilities, there have also been developments in the education of health professionals. It is recognised that a better health system for people with intellectual disabilities means a more educated and disability-aware workforce. The following are the main examples of policy-driven literature in the area.

Towards Best Practice in the Provision of Health Services for People with Disabilities in Ireland (2003) – National Disability Authority

Submission to Working Group on Undergraduate Medical Education and Training Response Form (2005)

Oral Health and Disability: The way forward (2005) – National Disability Authority

Eligibility

Recently, efforts have been made to synthesise information on services for people with intellectual disabilities in order to make provisions more accessible. Comhairle, a national organisation that is responsible for providing advice and information on public services, has stated that it has a “particular remit to support people with disabilities in accessing their entitlements”. Their booklet, ‘Entitlements for People with Disabilities’ explains a long list of benefits, payments, health and community care services, education, housing and employment entitlements and legal rights that may apply to a person with a disability.

In Ireland, there are no enshrined legalised rights to healthcare for people with or without disabilities (McDevitt, 1998). It has been suggested that the government should create legislation in this area based on a statement of rights and key objectives (NDA – Submission to the Minister for Health and Children on Health Strategy, 2001). As it stands, people with intellectual disabilities are entitled to general health services such as medical care, medications, hospital services, and dental, aural and optical services on the same basis as individuals without a disability. Entitlement to these services is governed by the Health Act of 1970, where adults are defined as people of 16 and over. Recent changes to the organisation of the HSE (formerly the health boards) did not alter the rules on entitlement to services (Relate, April 2005).

There are two categories for entitlement to health services that reflect what could be termed full eligibility and limited eligibility that are means-tested. Although based on income, individual circumstances may be taken into account in deciding who is eligible, but the methods used to determine this are not evident. Full eligibility means that's the individual has a standard medical card, which means that the individual is entitled to free GP services, free medications, free in-patient and out-patient public hospital services, free dental, ophthalmic and aural services, free public health nursing and free maternity and infant care services. In certain circumstances, people with limited eligibility are entitled to 'doctor-only' medical cards that ensure free GP services, subsidised medications, free in-patient and out-patient public hospital services, and free maternity and infant care services. Non-medical card holders are entitled to subsidised medications, free in-patient and out-patient public hospital services and free maternity and infant care services (Relate, April 2005).

Current Health Services

In Ireland, a strong link exists between health care and disability, as services relating to disability have historically been under the auspices of health. The Department of Health and Children and the Health Service Executive (HSE) areas have responsibility in providing both health and social welfare services to people with disabilities in Ireland. Although the names of these departments seem to convey rather a narrow focus on health, their brief is actually quite broad, encompassing a range of social care and health related services. The HSE areas, created to replace the old health board system originally in place in the country, provide health related services for people with intellectual disabilities as well as for people with physical, sensory or mental health disabilities. Many of the services provided by the HSE are not covered by specific legislation, but they are obliged to provide services in certain domains such as hospital services.

Service delivery is planned by the HSE in their National Service Plan (2005). Since the publishing of the National Health Strategy in 'Quality and Fairness: A Health System for You' (2001), it has been the aim of the HSE to provide more and better services for people with disabilities – "Services for persons with disabilities seek to enable each individual with a disability to achieve his/her full potential and maximise independence including living as independently as possible" (HSE, National Service Plan, 2005, p.8). The HSE National Service Plan (2005) also stated that there would be 270 extra funded residential places, 400 extra funded day care places and 90 extra funded respite places for people with intellectual disability and autism. In addition, there will be 60 new places for people with severe disabilities that are inappropriately placed, 90 additional funded rehabilitative training places and an extra 200,000 hours of home support and personal assistance.

Multidisciplinary health services are also available to people with intellectual disabilities through HSE community based provisions, although the services available may differ from one HSE area to another. Community based services include health services such as public health nurses, occupational therapists, physiotherapists, speech and language therapists, social workers, home help and personal assistance, and meals on wheels. As these are the services that are designed to meet the needs of many parts of the community (children, the elderly, people with other types of disabilities), the demand usually out-weighs the extent of the resources. In some cases, people with disabilities have priority in accessing certain services. Just over 18,000 people with intellectual disabilities are known to avail of these types of services (NIDD, 2005). Details on the provision of such services are given below. These inputs were recorded on the basis that the individual had received or would utilise that service at least four times in a year.

Table 4: Provision of multidisciplinary health support services

National Intellectual Disability Database Committee Annual Report, 2005 (p. 54)

	<6 years	7-18 years	>19 years	Total
Medical services	883	962	5264	7109
Nursing	784	833	3083	4700
Nutrition	250	395	1806	2451
Occupational therapy	902	1253	1482	3637
Physiotherapy	1183	1222	2116	4521
Psychiatry	92	417	5379	5888
Psychology	1072	2065	3906	7043
Social work	1128	2312	5715	9155
Speech and language therapy	1397	2731	805	4933
Other	614	1008	3017	4639
Total	1822	4490	12,087	18,399

Another element to service provision is the promotion of health related services and information dissemination that is directed at people with intellectual disabilities. The Health Promotion Unit, a unit of the Department of Health and Children, is responsible for the dissemination of health-related materials to the public. To date, there have been no specific campaigns aimed at people with intellectual disabilities.

Research on Health in People with Intellectual Disabilities

As part of their remit, the NDA have initiated and guided research into the health of people with disabilities in Ireland. To date, there has been minimal research into the health of people with intellectual disabilities. Consequently, much of the research mentioned below, although it is very informative and for the most part applicable to this group of people, may not reflect the uniqueness of the situation for people with intellectual disabilities. The Living in Ireland Survey, conducted by the ESRI as part of the European Community Household Panel (ECHP) was the first longitudinal survey of health and social participation in Ireland. The NDA subsequently published the relevant findings and analysis in a report entitled 'Disability and Social Inclusion in Ireland' (Gannon and Nolan, 2005). The Living in Ireland Survey investigated social inclusion and exclusion for people with disabilities under four main headings – education, earnings, poverty and deprivation and social life and social participation. The findings, however, reflected the health of the long-term disabled as well as those who has a long-term illness.

Undoubtedly, the most important health related NDA publication to date has been 'Towards Best Practice in the Provision of Health Services for People with Disabilities in Ireland' (2003). This report contained an assessment by Dr Jane Pillinger of the state of health services in Ireland. Since this investigation was carried out, it has been a key tool in the mapping and progression of health services in Ireland.

The NDA has also published on more specific health-related topics. In light of the National Disability Strategy, it was recognised that oral health is a major health issue for people with disabilities. Oral health is central to general health, and it is recognised that there are definite inequalities in this area. The National Oral Health Surveys were first carried out in 2002 and 2003, which found that children with disabilities had more dental decay than children without a disability, and that this was more likely to go untreated. Adults with disabilities also had more dental decay and more missing teeth (NDA, 2005). In 2005, the NDA published a report entitled 'Oral Health and Disability: The way forward'. This document provided a series of recommendations for advancing dental services and the promotion of oral health to people with disabilities.

The Department of Health and Children has also published material in the area of oral health, that is specifically related to people with intellectual disabilities (Crowley, Whelton, Murphy,

Kelleher, Cronin, Flannery and Nunn, 2003). Research has also been carried out in conjunction with the Health Boards, as they were previously called. McAllister and Bradley (2003) compared children in mainstream schools to children in special education and found that the former had more decay-free teeth than the latter but that children with special needs had higher levels of gum disease. Research has also been conducted in the north-eastern HSE area into an early intervention on oral health for children with disabilities (NDA, 2005).

A recent study commissioned by the NDA and conducted by NUI Galway has suggested that there are still inequalities for people with disabilities in accessing health services in Ireland. Further to this ‘The Experiences of People with Disabilities in Accessing Health Services in Ireland: Do inequalities exist?’ (D’Eath, Sixsmith, Cannon and Kelly, 2005) has stated that people with intellectual disabilities are one of the most disadvantaged groups, alongside deaf people and people with a disability and a mental health problem. It was found that the health system is such that it takes significant input and support from family and carers in order to correct for the inequalities in the system of access.

The NDA has recognised the need for specific information on the lives and welfare of people with disabilities. They are currently involved in a project measuring the health of people with disabilities in Europe (MHADIE) that is led by the World Health Organisation. Information on this project can be found on their website (www.nda.ie). Research is conducted on an ongoing basis in some of the voluntary organisations that provide services and information to people with intellectual disabilities. It is beyond the remit of this discussion to give details on current research in Ireland, but certain agencies are more active than others in this area, for example the National Federation of Voluntary Bodies (www.fedvol.ie).

It should also be mentioned that there is a general paucity of information on the health of people with intellectual disabilities compared to the general population, and also the occurrence of certain medical conditions in people with intellectual disabilities. This may be due to inadequacies in the research area itself. For example Ireland does not have any data on the prevalence of epilepsy besides extrapolated data, which makes comparisons very difficult.

Data on Life Expectancy

There are no official statistics for life expectancy in people with intellectual disabilities in Ireland. This question is difficult to answer, especially when taking into account that the incidence of disability increases with age, and that a significant number of people acquire disabilities during their lifetime (Gannon and Nolan, 2005). As the last census of population conducted in 2002 did not classify people in terms of whether they had an intellectual impairment or not, it is impossible to obtain figures on the average length of life for this population. What is clear from this census, however, is that life expectancy is increasing for the population in general which is likely to also be the case for people with intellectual disabilities. In 2002 the life expectancy at birth was 75.1 for males and 80.3 for females (CSO, Irish Life Tables No. 14 2001-2003, 23 June 2004).

References

Barron, S. and Mulvaney, F. (2005) National Intellectual Disability Database Committee Annual Report 2005. Health Research Board, Dublin.

Central Statistics Office (2002, 2004) Quarterly National Household Surveys – Disability module Q2 2002; Equality module Q4 2004 (www.cso.ie).

Central Statistics Office (June, 2004) Irish Life Tables No. 14 2001-2003. Central Statics Office, Dublin.

- Central Statistics Office. Census 2002 (www.cso.ie)
- Comhairle (2005) Entitlements for People with Disabilities (www.comhairle.ie)
- Comhairle (April, 2005) Relate (www.comhairle.ie)
- Commission on the Status of People with Disabilities (1996) A Strategy for Equality. Stationary Office, Dublin.
- Crowley, Whelton, Murphy, Kelleher, Cronin, Flannery and Nunn (2003) Oral health of adults with an intellectual disability in residential care in Ireland. The Department of Health and Children, Dublin.
- D'Eath, M; Sixsmith, J; Cannon, R. and Kelly, L. (2005) The Experience of People with Disabilities in Accessing Health Services in Ireland: Do inequalities exist? National Disability Authority, Dublin.
- Department of Health and Children (2001) Quality and Fairness: A health system for you. Department of Health and Children, Dublin.
- Department of Health and Children (2003) The National Health and Lifestyles Survey 2002. Department of Health and Children, Dublin.
- Elliott, I; Nunn, J. and Sadlier, D. (eds) (2005) Oral Health and Disability: The way forward. National Disability Authority, Dublin.
- European Social Survey 2002/2003. Survey data available at: <http://ess.nsd.uib.no>
- Gannon, B. and Nolan, B. (2004) Disability and Social Inclusion in Ireland. The Equality Authority and National Disability Authority, Dublin.
- Health Service Executive (2005) National Service Plan 2005. Health Service Executive, Dublin.
- Martin, Meltzer and Elliott (1988) The Prevalence of Disability Among Adults – OPCS surveys of disability in Great Britain. HSMO, London.
- McAllister and Bradley (2003) Cited in Elliott, Nunn and Sadlier (eds) (2005) Oral Health and Disability. National Disability Authority, Dublin.
- McConkey, R; Mulvaney, F. and Barron, S. (2006) Adult persons with intellectual disabilities on the island of Ireland. Journal of Intellectual Disability Research, 50(3): 227-236.
- McDonnell, P.(2003) Education policy. In Quinn, S. and Redmond, B. Disability and Social Policy in Ireland. UCD Press, Dublin.
- Mulvaney, F. and Barron, S. (2003) National Intellectual Database Committee Annual Report 2002. Health Research Board, Dublin.
- NAMHI (2003) Who Decides and How? People with Intellectual Disabilities – Legal Capacity and Decision Making. NAMHI, Dublin.
- National Disability Authority – tns-mrbi (2004) Social Participation and Disability. National Disability Authority, Dublin.
- National Disability Authority (2001) Submission to the Minister of Health and Children on Health Strategy. National Disability Authority, Dublin.

- National Disability Authority (2001) Submission to the Review of the National Anti-Poverty Strategy on Health. National Disability Authority, Dublin.
- National Disability Authority (2003) Review of Access to Mental Health Services for People with Intellectual Disabilities. National Disability Authority, Dublin.
- National Disability Authority (2003) Towards Best Practice in the Provision of Health Services for People with Disabilities in Ireland. National Disability Authority, Dublin.
- National Disability Authority (2006) Ageing and Disability: A discussion paper. National Disability Authority, Dublin.
- National Disability Authority (January 2006) Submission to the National Steering Committee on the Development of a Men's Health Policy. National Disability Authority, Dublin.
- National Disability Authority (Sept 2005) Submission to the Department of Health and Children on the Strategic Review of Disability Services. National Disability Authority, Dublin.
- National Oral Health Surveys (2002, 2003) Cited in Elliott, Nunn and Sadlier (eds) (2005) Oral Health and Disability. National Disability Authority, Dublin.
- Office of the Ombudsman (June, 2001) Presentation to the Joint Committee on Health and Children – Nursing Home Subventions: An investigation by the Ombudsman regarding payment of nursing home subventions by health boards. Dublin: Office of the Ombudsman.
- Quinn, S. (2003) Health services and disability. In Quinn, S. and Redmond, B. Disability and Social Policy in Ireland. UCD Press, Dublin.
- Quinlivan, S. (2004) Law and disability in Ireland. In Noonan-Walsh, P. and Gash, H. Lives and Times: People with Intellectual Disabilities. Dublin.