
Implementing the National Disability Strategy



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Inclusion Ireland Position Paper

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List of Abbreviations

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| CIB | Citizens Information Board |
| CRPD | Convention on the Rights of Persons with Disabilities |
| CSO: | Central Statistics Office |
| DSG: | Disability Stakeholders Group |
| ECHR: | European Convention on Human Rights. |
| EPSEN: | Education for Persons with Special Educational Needs Act 2004 |
| HIQA: | Health Information and Quality Authority (HIQA) |
| HRB: | Health Research Board |
| HSE: | Health Services Executive |
| IHRC: | Irish Human Rights Commission |
| NAS: | National Advocacy Service |
| NCSE: | National Council for Special Education (NCSE) |
| NDA: | National Disability Authority |
| NDS: | National Disability Strategy |
| NDSIG: | National Disability Strategy Implementation Group |
| PAS: | Personal Advocacy Service |



Glossary of Terms

Assessment of need: an assessment of need is an assessment of the full range of a child's needs associated with his or her disability as set out in Part 2 of the Disability Act 2005.

Cost of disability: refers to the economic cost of disability in terms of the additional spending needs that arise due to disability.

National Advocacy Service: an independent advocacy service for people with disabilities. It is funded by the Citizens Information Board.

National Disability Strategy: launched in September 2004, it comprised the Disability Bill, 2004; The Education for Persons with Special Educational Needs Act, 2004; The Comhairle (Amendment) Bill, 2004 and a multi-annual investment programme for disability support services for the period 2006-2009.

National Disability Strategy Implementation Group: a high level group comprising members from government departments; the Disability Stakeholders Group (DSG); the National Disability Authority (NDA); and the County and City Managers Association. This group was established in November 2011.

Disability Act 2005: is the central element of the National Disability Strategy. It is designed to support the provision of disability-specific services and improve access to mainstream public services for people with disabilities.

Congregated setting: a residential service accommodating ten or more people.

Disability Stakeholders Group: established in 2006 as a mechanism to maintain involvement of disability umbrella organisations in national disability policy.

Human rights: are rights inherent to all human beings, regardless of nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status.



Implementation plan: the current Programme for Government includes a commitment to publish a realistic implementation plan for the NDS.

Sectoral plan: the plans published by six government departments showing how they will address key disability issues.



Foreword

Inclusion Ireland is the national organisation advocating for the rights of people with intellectual disabilities in Ireland. Established in 1961, our vision is of a society where people with intellectual disabilities live and participate in the community with equal rights as citizens. Our focus is on the realisation of the core principles and values expressed in the United Nation's Convention on the Rights of Persons with Disabilities (CRPD).

Inclusion Ireland recognises that the current government is committed to publishing a realistic implementation plan for the National Disability Strategy (NDS) and the engagement of the Minister of State, Department of Health and Department of Justice, Equality & Defence with responsibility for Disability, Older People, Equality & Mental Health in driving the process through her chairmanship of the NDS Implementation Group (NDSIG).

Inclusion Ireland has contributed to the drafting of an implementation plan through its participation on the Disability Stakeholders Group (DSG). The DSG, which was established by the Minister, is made up of a number of stakeholders who represent varying views on the priorities for government in implementing a national disability strategy. In June 2012, the DSG submitted a comprehensive document to the NDSIG outlining many of the issues it wished to see incorporated into the implementation plan for the NDS. The government's implementation plan for the NDS seeks to encourage government departments to meet their obligations across a broad spectrum of policy areas which impact on the support needs of people with physical, sensory and intellectual disabilities.

As this document points out, the environment has changed quite considerably since the legislation which comprises the NDS was first published and key pieces of that legislation remain to be fully commenced.



As a national organisation advocating for the rights of people with intellectual disabilities, Inclusion Ireland sets out here what it believes the government's implementation plan for the NDS must address.

Austerity is having a serious impact on the lives of people with intellectual disabilities and their families; cuts to respite services; non-replacement of front-line staff providing services to children with disability; cuts to home help and personal assistant hours; restriction on funding for school leavers; withdrawal of payments to people with intellectual disabilities working in sheltered work and attending rehabilitative training and the erosion of community based supports and programmes undermine belief in the Programme for Government's commitment to ensure that 'every person with a disability would be supported to enable them as far as possible to lead full and independent lives to participate in work and in society and to maximise their potential'.

Inclusion Ireland has become increasingly concerned that these types of policy decisions and actions which impact so severely on the lives of people with disabilities, and the failure to-date to fully implement the legislation which form the architecture of the NDS is incongruous with the government's desire to publish an Implementation Plan. Inclusion Ireland in making the following observations about the government's emerging implementation plan for the NDS seeks to advocate for the rights of people with intellectual disabilities.

Paddy Connolly

CEO

Inclusion Ireland



1. Introduction

A National Disability Strategy (NDS) was introduced by the government in 2004, with the overall aim of supporting the equal participation of people with disabilities in society. The current Programme for Government includes a commitment to publish a realistic implementation plan for the NDS including sectoral plans with achievable timescales and targets within available resources. The Minister for Disability, Older People, Equality & Mental Health has established a new NDS Implementation Group (NDSIG) to guide the development of this plan and monitor its subsequent implementation.

Inclusion Ireland has been invited by government to contribute to the preparation and monitoring of the implementation of the NDS. We are guided in this work through the collaboration and active involvement of our membership, which include people with intellectual disabilities; their family members; academics; community and voluntary organisations providing services and supports to people with an intellectual disability; and parent and friend groups throughout Ireland.

This document summarises the views of Inclusion Ireland on the NDS and its implementation to date. It outlines the core elements of the NDS and identifies where progress has been made. It provides a summary of the changing context since the announcement of the NDS in 2004 and identifies some of the policy and legislative gaps which remain to be addressed, and identifies issues of priority.



2. People with intellectual disabilities

Inclusion Ireland is concerned that people with intellectual disabilities continue to have their fundamental rights denied and face significant obstacles in participating in society on an equal basis with others. According to data from the most recent Census of Population, there are over 57,700 people with intellectual disabilities in Ireland (CSO, 2011). Eight out of ten people with intellectual disabilities have another disability.

Inclusion Ireland is concerned about the situation of those people with intellectual disabilities who receive residential and day services. 90% of all day and residential services provided to children and adults with an intellectual disability take place in group settings that are segregated from the rest of the community.¹ The most recent data available from the Health Research Board shows that 8,214 people with intellectual disabilities were in receipt of a full-time residential service in 2011. 26,744 people with intellectual disabilities availed of at least one day programme in 2011 (HRB, 2011). These services are not regulated. They are not monitored or inspected by the Health and Information Quality Authority. Independent advocates have no statutory powers to enter residential or day services or to make enquiries on matters affecting people in receipt of these services

Inclusion Ireland is particularly concerned about people with profound or severe intellectual disabilities who are accommodated in congregated settings. A congregated setting is defined as an institution accommodating more than 10 people.

'Congregated provision is in breach of Ireland's obligations under UN Conventions. The provision contradicts the policy of mainstreaming underpinning the Government's National Disability Strategy. We now know what needs to be done to change people's lives and why their lives must change. This knowledge brings with it an obligation to act.' (HSE, 2011:14).

¹ Department of Health, Report of Disability Policy Review, (2011:9)



Around 4,000 people with an intellectual disability living in congregated settings in Ireland. The majority of people living in congregated settings have a profound intellectual disability and have been institutionalised for at least 15 years (HSE, 2011).

In 2010 the Irish Human Rights Commission (IHRC) carried out an enquiry into the situation of people with intellectual disability in a congregated setting where day and residential services are provided to adults and children with a disability. The report of that enquiry found that the rights of people with a disability were not adequately protected or promoted. It recommended immediate ratification of the CRPD and full implementation of the NDS.

‘To give greater protection to people with disability, the government should fully implement the Disability Act, introduce mental capacity legislation and ratify the UN Convention on the Rights of Persons with Disability. This convention stresses that people with a disability should be fully integrated in the community and be able to live with optimum independence and functionality. It should be ratified without delay and incorporated into Irish law.’ (Irish Human Rights Commission, 2010)

There were over 200 people with intellectual disabilities accommodated in psychiatric hospitals in 2011 (HRB, 2011). The conditions in these facilities can be extremely poor.

Unlike other residential services accommodating people with intellectual disabilities, psychiatric hospitals are inspected by statutory agencies. A recent inspection of one psychiatric hospital found residents with intellectual disabilities ‘engaged in rocking, self stimulating behaviour, sleeping or just sitting’.² In a ward accommodating people with intellectual disabilities, the inspectors found there were no curtains around the beds and no locks on toilet doors. The report strongly criticised the failure to provide essential therapies for residents with intellectual disability. There is only one approved centre for people with intellectual disabilities experiencing mental

² Report of the Inspector of Mental Health Services into St. Senan’s Hospital, November 2012



health difficulties in Ireland. There is no dedicated unit providing for the treatment of people with intellectual disabilities also experiencing acute mental health difficulties.³

People with intellectual disabilities continue to be excluded from the labour force and the labour market. Only 20% of people with a disability are at work compared with 50% of the general population.⁴ The employment rate of people with intellectual disabilities is around 5%.⁵ The CRPD places an obligation on the government to recognise the right of persons with disability to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and a work environment that is open, inclusive and accessible to persons with disability.⁶

The exclusion of people with intellectual disability from employment means that many are reliant on welfare payments as their only source of income. It is therefore no surprise that people with intellectual disability experience high levels of poverty and deprivation. A 2009 survey of living conditions found that people with disability experienced deprivation levels of 42%, which was by far the highest level compared with unemployed people, students or older people.⁷ These cuts run contrary to the CRPD, particularly with regard to the right to an adequate standard of living and social protection.⁸

'Passive income support alone is not sufficient if poverty and social exclusion are to be comprehensively addressed.' (National Action Plan for Social Inclusion, 2007:42).

Inclusion Ireland is also concerned with the negative attitudes towards people with intellectual disabilities. A recent national survey found a hardening of attitudes

³ Annual Report 2011 including the Report of the Inspector of Mental Health Services, Mental Health Commission, 2012

⁴ Profile 8: Our Bill of Health - Health, Disability and Carers in Ireland, CSO, 2012

⁵ calculated from National Intellectual Disability Databases, 2008-2011, Health Research Board

⁶ Article 27 UN Convention on the Rights of Persons with Disabilities

⁷ Survey on Income and Living Conditions (SILC), Central Statistics Office, 2010

⁸ Article 28 UN Convention on the Rights of Persons with Disabilities



towards people with intellectual disabilities. The survey found that one out of every two people surveyed believe that people with intellectual disabilities do not have the same right to sexual relationships as everyone else. 60% of people surveyed believe that people with intellectual disabilities should not have children. 40% of respondents said they were opposed to educating children with an intellectual disability in mainstream settings.⁹

The CRPD places an obligation on the government to foster respect for the rights and dignity of persons with an intellectual disability and to promote awareness of the capabilities and contributions of persons with disability.¹⁰

Many people with intellectual disabilities are accommodated in congregated settings. These places are segregated from the rest of the community. There are no regulations, standards or inspections of these services. Despite their vulnerability, people living in institutions do not have access to an advocacy service with statutory powers to make enquiries on their behalf.

Unemployment is disproportionately higher for people with disabilities leading to unacceptable levels of poverty and deprivation. Public attitudes towards people with a disability are becoming increasingly negative. Government failure to act address inequalities runs contrary to the principles and standards of international human rights treaties.

⁹ National Survey of Public Attitudes to Disability in Ireland, National Disability Authority 2012

¹⁰ Article 8 UN Convention on the Rights of Persons with Disabilities



3. The National Disability Strategy

The National Disability Strategy (NDS) was announced by government in 2004. The NDS built on the equality framework of the Employment Equality Act, 1998; the Equal Status Act, 2000; the Equality Act, 2004; and the progress that had been made in mainstreaming services for people with disabilities. The NDS contained three pieces of legislation and a multi-annual investment programme for disability services for the period 2006 to 2009.

The legislative components of the NDS were The Disability Act 2005; The Education for Persons with Special Educational Needs Act 2004 and The Citizens Information Act 2007.¹¹ The following section provides a description of the legislative provisions of the NDS and will identify some

3.1 The Disability Act 2005

The Disability Act 2005 is a key component of the National Disability Strategy. The Disability Act sets out the legal requirements of public bodies, subject to certain considerations. The Act provides for an independent assessment of individual needs, a related service statement and independent redress and enforcement for people with disabilities. It also places an obligation on public bodies to make their buildings, information and services accessible to people with disabilities and to integrate disability service provision with mainstream services. The Disability Act also provides for the publication of sectoral plans for six government departments. Other provisions of the Disability Act include restrictions on the use of information from genetic testing; an obligation on public bodies to be pro-active in employing people with disabilities; and the establishment of a Centre for Excellence in Universal Design.

¹¹ The Disability Act 2005 and Citizens Information Act 2007 were originally introduced as the Disability Bill 2004 and the Comhairle Amendment Bill 2004



The passing into law of the Disability Act followed a long campaign by people with disabilities, parents and other advocates for the introduction of rights-based disability legislation. A previous attempt at introducing a Disability Bill was withdrawn in 2002 following protests over its failure to include rights-based access to services. The Disability Act 2005 still fell significantly short of the comprehensive rights-based legislation that people with disabilities and their advocates had campaigned for.

One of the main concerns of people with disabilities and their representative organisations was the omission from the Act of the right to seek judicial remedies where any of the provisions of the Act are not carried out. These concerns were shared by the Irish Human Rights Commission and the UN Committee on Economic, Social and Cultural Rights.¹²

The key provision of the Disability Act was the right to an Assessment of Need for health and education and an entitlement to services set out in a related Service Statement. The Act provides that a person with a disability, or a person advocating on their behalf may apply for an assessment of the health and education needs occasioned by their disability. The purpose of the assessments is to identify these needs and the services required to address these needs, without regard to the cost or the capacity to deliver these services. The Act requires the HSE to appoint assessment officers to carry out or arrange the carrying out of the assessments. This is provided for in Part 2 of the Act.

However, Part 2 has not been fully implemented. At present only children who were born after 01 June 2002 are entitled to apply for an assessment of needs under the Act (regardless of their age at time of application). The Act was to be commenced for those children aged 5-18 years in tandem with the implementation of the Education for Persons with Special Educational Needs (EPSEN) Act 2004. It is a requirement under the Disability Act that assessments of need are completed within six months of receipt of an application. However, according to figures published by the HSE, 3,361 applications were received for assessments of needs in 2011.

¹² Shadow Report to the Third Periodic Report of Ireland under the International Covenant on Civil and Political Rights, FLAC, ICCL, IPRT, (2008)



However, only 712 of these applications were completed within the timeframe specified in the Act.¹³

It has been reported that the HSE has sought to have the timeframe specified in the Act extended so that it could meet its legal requirements. The HSE has also proposed decreasing the number of assessment reports for children who are in the education system.¹⁴

Inclusion Ireland regularly deals with calls from parents who are experiencing difficulties and delays in having their children's needs assessed within the timeframe set out in the Act. Parents have reported that they have been encouraged not to put their children through the assessment process. There is a significant level of confusions amongst parents. The Ombudsman & Information Commissioner has also criticised the administration of the assessment of need under the Act.¹⁵

Section 16 of the Disability Act provides for the appointment of a Disability Appeals Officer by the Minister for Health and Children. The DAO provides an independent appeals service to people who wish to appeal against a finding or recommendation of a complaints officer of the HSE, or against the failure of the HSE or an education service provider to implement a recommendation of a complaints officer. However, the post of Disability Appeals Officer was vacated in December, 2011 and remains unfilled. The post remains unfilled despite several assurances that a suitable person would be appointed by the Minister for Health & Children a matter of urgency. As mentioned previously, the Act does not provide for the right of people with disabilities to seek judicial remedies where any of the provisions of the Act are not carried out. Consequently, parents of children with a disability have no access to independent complaints, appeal or redress in respect of the assessment of need.

The Citizens Information Act 2007 provides for a Personal Advocacy Service (PAS) to be established. One of the functions of PAS is to support or assist people in

¹³ HSE, National Service Plan 2012, Supplementary Report, September 2012

¹⁴ Major delay in assessing disabled children', *Irish Times*, Monday, May 7, 2012

¹⁵ Speech by Emily O'Reilly, Ombudsman & Information Commissioner, 23 February 2012



making applications and appeals in respect of the assessment of need under the Disability Act. However, the PAS has not been introduced as the section of the Citizens Information Act providing for it has not been implemented.

Many parents of children with an intellectual disability have contacted Inclusion Ireland complaining of a lack of information about the administration of the assessment and inconsistencies with how assessments of need are undertaken. These concerns are reflected in submissions made as part of the review of the operation of the Disability Act.¹⁶

The Health and Information Quality Authority (HIQA) published standards in relation to how the statutory assessment of need should be undertaken; there is no systematic national monitoring of compliance with the standards. The Disability Act contains no provision for the monitoring or review of the standards developed by HIQA. The review of the operation of the Disability Act, which was initiated in 2010, has not been completed.

In 2011 the National Disability Authority published a report on the practice of assessment of need under the Disability Act. It found that the assessment of need is being placed under significant pressure as a direct consequence of the failure to implement education assessments under the EPSEN Act. The report also highlighted the incompatibility of the assessment of need process with the resource allocation rules currently operated by the Department of Education. According to this report, the failure to commence the relevant sections of the EPSEN Act, the Disability Act 2005 is being used as means to expedite special education assessments.¹⁷

The NDA report recommended that urgent action be taken to address this issue. It is the experience of Inclusion Ireland that many children in school who require a psychological assessment cannot avail of one in a timely manner. Even though

¹⁶ Department of Community, Equality and Gaeltacht Affairs (2010), Review of the Operation of the Disability Act 2005

¹⁷ National Disability Authority (2011), Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005



many of these children do not have a disability they are applying for an assessment of needs under the Disability Act to expedite an assessment of their educational needs. This is placing unnecessary pressure on health care assessors.

The inconsistent approach to assessing children under the Disability Act, the failure to commence the relevant section of EPSEN Act (see section 3.2 of this document) and the absence of an independent appeals mechanism means that parents of children with a disability are faced with a multitude of bureaucratic obstacles in the search for vital therapeutic supports for their disabled children at a crucial time in their child's social, physical and intellectual development.

Failure to fully implement the Disability Act has resulted in a two-tier assessment of need system which discriminates against who do not qualify on age grounds. There is no consistency in how assessments are carried out, and failure to comply with the statutory timeframe for completing assessments. The statutory independent appeals mechanism has been removed.

In addition to providing for an assessment of health and education needs of qualifying persons, the Disability Act 2005 places an obligation on government departments and public bodies to make their buildings and services accessible to people with disabilities. It also requires the preparation of Sectoral Plans to support continued improvements in key areas of public service provision. Sectoral plans set out, for each of these departments and the public bodies under their aegis, the programme of measures to be taken in relation to the provision of services for people with disabilities.

Sectoral plans were published in 2006 by the departments of Health and Children; Social and Family Affairs; Transport; Environment, Heritage and Local Government; Communications, Marine and Natural Resources; and Enterprise, Trade and Employment.

The Disability Act did not place a requirement on the Department of Education or Justice and Equality to publish sectoral plans. It was felt that implementation of the EPSEN Act would cover all of the Department of Education's core obligations in



respect of people with disabilities. It is unclear why the Department of Justice was not required to publish a plan. No sectoral plans have been published since 2006.

The current programme for government includes a commitment to publish a realistic implementation plan for the NDS, including sectoral plans with achievable time scales and targets within available resources. Among the recommendations made in submissions to the review of the operation of the Disability Act was that every government department should be obliged to publish a sectoral plan.¹⁸ Inclusion Ireland endorses this view. The Implementation Plan for the NDS should contain an expressed commitment to publish new sectoral plans. The Department of Education and Skills and the Department of Justice should be required to publish plans.

3.2 The Education for Persons with Special Educational Needs Act 2004

The Education for Persons with Special Educational Needs Act 2004 (EPSEN) was signed into law in 2004. The passing of the Act marked a fundamental shift in the way in which the educational system would meet the needs of those with special educational needs. The Act provides for a right to inclusive education by way of statutory rights to assessment, preparation and review of individual education plans and an independent complaints and appeals mechanisms. The Act was to be implemented over a number of years with full implementation of its provisions to take place by October 2010. In 2008, a decision was made to suspend implementation of the remaining provisions of the Act.

Under the Act, the National Council for Special Education (NCSE) was established to improve the delivery of education services to persons with special educational needs. The NSCE was established on 01 October 2005. In 2006 the NCSE prepared an Implementation Report which set out the sequence in which the remaining provisions of the Act should be commenced. The report estimated that the total

¹⁸ Department of Community, Equality and Gaeltacht Affairs (2010), Review of the Operation of the Disability Act 2005



investment on the education side to implement in full the provisions of the Act would be €397m over the five year period for implementation.¹⁹

The provision of an independent appeals mechanism was seen by parents as a key element of the EPSEN Act. Under the Act, a Special Education Appeals Board (SEAB) was established to hear complaints and determine appeals. The SEAB was established in 2007 and developed a system for complaints and appeals. Between 2007 and 2010 the Department spent over €260,000 funding the operations of the SEAB. An allocation of €70,000 was made for 2010. However, the term of office of the inaugural board ended in April 2010 and no new board has been appointed.

The failure of the government to fully commence the EPSEN Act runs contrary to the principles of the UN Convention on the Rights of Persons with a Disability (CRPD). Under Article 24 of the CPRD, the government is obliged to ensure that children with a disability are not excluded from the general education system on the basis of disability.

Cuts to education supports to children with special education needs by successive governments are compounded by increasing class sizes, which also put children with a disability at a disadvantage. This is preventing many children with a disability from reaching their potential and causing others to regress. It is a concern that 40% of respondents to an NDA survey are opposed to educating children with an intellectual disability in mainstream settings.²⁰

Young adults with an intellectual disability, those on the autism spectrum and those with an acquired brain injury exiting school have the right to participate in and benefit from educational opportunities. The practice of transferring these young people to the health sector is incompatible with their right to further compensatory or adapted education.

¹⁹ Implementation Report: Plan for the Phased Implementation of the EPSEN Act 2004, National Council For Special Education, 2006

²⁰ National Survey of Public Attitudes to Disability in Ireland, NDA, 2012



The Department of Education did not have to produce a Sectoral Plan under the Disability Act 2005 as it was felt that implementation of the EPSEN Act would cover all of the department's core obligations in respect of people with disabilities. The absence of full implementation of the EPSEN Act now requires the publication of a Sectoral Plan by the Department of Education as part of the implementation plan for the NDS. The current Programme for Government contains a commitment to publish a plan for the implementation of the EPSEN Act 2004. This should be published without delay.

3.4 The Citizens Information Act 2007

The Citizens Information Act 2007 replaced the Comhairle Amendment Bill 2004 and the Comhairle Act 2000. The Act changed the name of Comhairle to the Citizens Information Board (CIB). CIB is the statutory agency responsible for supporting the provision of information, advice and advocacy to the public on a broad range of social and civil services. The Act empowers the CIB to 'support the provision of or to provide directly, advocacy services to individuals, in particular those with a disability, that would assist them in identifying and understanding their needs and options and in securing their entitlements to social services.'²¹

The Act also provides for the establishment of a Personal Advocacy Service to people with disabilities. Advocates employed by the Personal Advocacy Service would have a range of statutory powers. Under the legislation advocates would be have the power to enter residential settings accommodating people with disabilities and make enquiries in respect of persons accommodated therein. The legislation places a legal obligation on statutory and voluntary services providers to co-operate with an advocate in the performance of his or her duties. There is specific provision in the primary legislation for advocates to assist and support persons making applications and appeals for an assessment of need under Part 2 of the Act.

²¹ Citizens Information Act 2007, Section 4 (b)



The Citizens Information Act provides for the appointment of a Director with responsibility to oversee the operation of the Personal Advocacy Service (PAS). The vacancy for the position of Director was publically advertised in December 2007. However, no appointment was made and the PAS has not yet been established.

The National Advocacy Service for people with disabilities (NAS) was established by the Citizens Information Board in 2011. However, the NAS advocates do not have the statutory powers envisaged for the Personal Advocates in the Citizens Information Act. For example, NAS advocates do not have the authority to enter congregated settings and make enquiries on behalf of vulnerable residents. There is no statutory duty on public bodies or disability service providers to co-operate with NAS advocates. No Director has been appointed with responsibility to oversee the operation of the National Advocacy Service. The service is which is currently managed on a regional basis through the Citizens Information Services.

It has been reported that NAS has met with resistance, lack of co-operation and exclusion from public bodies including the HSE, Legal Aid Board and the Courts Service.²²

Inclusion Ireland has consistently called for the full commencement of the Citizens Information Act 2007 and the instruction of the Personal Advocacy Service as provided for in that legislation. This is particularly relevant to 8,500 people with intellectual disabilities that live in residential homes and of critical importance to the 4,000 people with severe or profound intellectual disabilities that continue to be accommodated in congregated settings.

There are a range of other forms of advocacy in addition to representative advocacy that should be available to people with disabilities. These include self-advocacy, peer advocacy, and citizen advocacy. These forms of advocacy are not mutually exclusive: A person may need to use a different type of advocacy to deal with

²² See *Irish Times*, Tuesday 30 October 2012 and *Irish Times*, Wednesday 31 October 2012



specific problems.²³ The Commission on the Status of People with Disabilities made these very recommendations its seminal report nearly 20 years ago.

The absence of a broad spectrum of advocacy supports impedes significant numbers of people with disabilities their right to self determination and autonomy. The CRPD places an obligation on the government to protect and promote these rights. The absence of a range of advocacy support impedes the rights of people with an intellectual disability to full and effective participation and inclusion in society, to attend social activities of their choice, and to have their say in the design and delivery of the services and supports they need.

In addition to a commitment to introduce the Personal Advocacy Service, the implementation plan for the National Disability Strategy should include an explicit commitment to the provision of broader advocacy provision and a process to engage with key stakeholders to explore how such provision might be resourced.

²³ Comhairle, Jigsaw of Advocacy, 2003:9



4. Implementing the NDS in a changed context

It is acknowledged that the implementation of the National Disability Strategy (NDS) must be considerate of the changes in the economic environment since 2004. Inclusion Ireland acknowledges that the difficult fiscal environment in which we currently find ourselves in is challenging. Equality of status is a fundamental question of human rights that takes precedence over economics.

'The decision to pursue equality of status for people with disability is not a question of economic calculation'.²⁴

Significant developments have taken place in the wider policy environment since the 2004. The current programme for government and social partnership agreement contain specific commitments to improving the lives of people with disabilities. These aim to ensure that the quality of life of people with disability is enhanced and that resources allocated reach the people who need them. In addition, a range of other significant disability-specific policies and strategies have been published and need to be integrated in the implementation plan for the NDS.

4.1 Policy Context

The current programme for government contains a number of commitments to improve the lives of people with disabilities. These commitments aim to ensure that the quality of life of people with disabilities is enhanced and that resources allocated reach the people who need them. Towards 2016, the current social partnership agreement also contains a number of high level goals related to disability. It contains a range of commitments to provide people with a disability with the opportunity to live a full life with their families and as part of their local community, free from discrimination.

²⁴ A Strategy for Equality, 1996



Disability commitments in the current **Programme for Government**:

- Facilitate people with disability in achieving a greater level of participation in employment, training and education;
- Introduce statutory standards and inspection of disability services;
- Develop specific strategies for elderly patients and those with intellectual disability who remain under the care of mental health services;
- Move a proportion of public spending to a personal budget model so that people with disability or their families have the flexibility to make choices that suit their needs best;
- Publish a plan for the implementation of the EPSEN Act 2004

Disability goals in **Towards 2016** – the current social partnership agreement:

- Every person with a disability would have access to an income which is sufficient to sustain an acceptable standard of living;
- Every person with a disability would, in conformity with their needs and abilities, have access to appropriate care, health, education, employment and training and social services;
- Every person with a disability would have access to public spaces, buildings, transport, information, advocacy and other public services and appropriate housing;
- Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and in society and to maximise their potential;
- Carers would be acknowledged and supported in their caring role.



The disability-related goals of the social partnership agreement are restated in other national policies, including the current National Action Plan for Social Inclusion (2007-2016). The implementation plan for the NDS should include an explicit commitment to implement the disability-related commitments that are contained in the the programme for government, the social partnership agreement and National Action Plan for Social Inclusion.

A number of other key disability-specific policies and strategies have been introduced since the National Disability Strategy (NDS) was announced in 2004. These policies contain a range of commitments to reform outdated services and measures to improve the lives of children and adults with a disability. These national strategies and policies cover areas like deinstitutionalisation, day service reform, housing, and the reform of the delivery of services to children. The commitments and recommendations contained in these reports should be key features of the implementation plan for the NDS.

Key disability-related policies and strategies

- Time to Move on from Congregated Settings (HSE, 2011)
- New Directions: HSE Day Services Implementation Plan (HSE 2012)
- Review of Autism Services: Past, Present and Way Forward (HSE, 2012)
- Report on Multi-Disciplinary Disability Services for Children (HSE, 2009)
- National Housing Strategy for People with a Disability (Dept of Environment, 2012)
- Report of Disability Policy Review (Dept of Health, 2011)
- Value for Money and Policy Review of Disability Services (Dept of Health, 2012)
- The National Carers' Strategy (Dept of Health, 2012)



4.2 HSE Reform Programme

The Health Services Executive (HSE) plays a crucial role in the lives of adults and children with intellectual disability. As mentioned previously, the HSE is responsible for the implementation of recommendations from a number of key policies and strategies. Implementation of these reforms will have an enormous impact on the lives of people with intellectual disabilities. However, the HSE Disability Unit is under-resourced and there is great uncertainty about the future within the agency. Frontline staff are not being replaced and consultation with families of children with disability and adults with disability appears non-existent or tokenistic. The reform programme planned in the area of intellectual disability and set out in government policy should be expedited as a matter of urgency.

Inclusion Ireland believes that the human rights of people with intellectual disabilities cannot be safeguarded and their lives will be severely curtailed unless the HSE Disability Unit has the resources and the leadership necessary to drive the major reform programme in the area of intellectual disability.

4.3 Convention on the Rights of Persons with Disability (CRPD)

One of the most significant developments to have occurred since the announcement of the NDS in 2004 has been the introduction of the UN Convention on the Rights of Persons with Disability (CRPD). The CRPD was adopted by the UN General Assembly in December 2006 and entered into force in May 2008.

The CRPD reaffirms the right of every person with a disability to self-determination, autonomy, equality and dignity. As well as reaffirming the human rights of people with disabilities, the CRPD sets out the steps that governments and public bodies must make to ensure that people with disabilities have their human rights protected, promoted and fulfilled. The CRPD is the first international human rights treaty of the 21st century.



'It is the task of national authorities; national human rights institutions and civil society organisations to ensure that the rights of people with disability as enunciated in the CRPD are promoted and protected.' Irish Human Rights Commission (2010)

Ireland was one of the first groups of countries to sign the CRPD in March 2007. In doing so, Ireland has demonstrated agreement to the principles enunciated in the CRPD and its intention to comply with its provisions. The government has stated its intention that the CRPD will be ratified as quickly as possible.

Ireland has yet to ratify the CRPD and is therefore not legally obliged to comply with its provisions at this time. However, States which have not ratified the CRPD may nonetheless be held accountable to the European Court of Human Rights (ECtHR). The ECtHR is using the CRPD as a benchmark for the interpretation of the European Convention on Human Rights (ECHR) in relation to the rights of people with disabilities.²⁵ It is also notable that Ireland has recently been elected to the United Nations Human Rights Council for the period 2013-2015.

An implementation plan for the National Disability Strategy provides an opportunity to make clear a shared national vision for people with disabilities. The vision, mission and principles of the CRPD should expressly underpin the implementation of the NDS. The implementation plan should identify the legal and administrative impediments to ratification of the CRPD and what measures the government needs to take to address these impediments. Other Governments have successfully embedded the CRPD in their National Disability Strategies.²⁶ It is also of significance that the European Union (EU) ratified the CRPD in 2011. This is the first time that the EU has become a party to an international human rights treaty

The implementation plan for the National Disability Strategy should take into consideration the significant developments that have taken place at European level since the NDS was announced in 2004. Two important developments have been the publication of the Council of Europe's Disability Action Plan 2006-2015 and the EU

²⁵ See European Court of Human Rights Case of *Sven Glor v Switzerland* 06, November, 2009

²⁶ Australian National Disability Strategy 2010-2020 and Disability Strategy for Northern Ireland



Disability Strategy 2010-2020. The rights of people with disabilities are also protected and promoted under the Charter of Fundamental Rights, and the European Convention on Human Rights.

The EU Parliament, the European Commission and the European Economic and Social Committee are all contributing to the advance of the rights of persons with disability in particular through more targeted use of structural funds to promote social enterprises, changes in public procurement in the context of competition policy, and advances in the regulations for private transport operators (March 2013). These advances are not yet reflected in Irish public policy and would have considerable benefit for people with intellectual disabilities and their families.

4.4 Legislative Reform

Inclusion Ireland is not sufficiently resourced to undertake a comprehensive review of all of the legislative requirements for alignment with the National Disability Strategy. However, as a result of our work with people with intellectual disabilities and their family members, we have identified the following areas of law where reform is needed.

The Lunacy Regulations Ireland Act (1871) provides for wardship proceedings when individuals are assessed as having no capacity. The effect of this law is that the State is denying basic human rights to thousands of people with disabilities. Once made a ward of court, an individual is denied the right to vote, to make a will, to travel abroad and to marry. This is a critical area requiring urgent legislative reform. Article 12 of the CRPD reaffirms the right of every person to have equal recognition before the law. This requires that a person's legal capacity, including the capacity to act, is equally recognised. The CRPD says that Governments must take measures so that people with disabilities are entitled to enjoy legal capacity on an equal basis with others and that they should have access to the supports required to enjoy legal capacity.



The implementation plan for the NDS must set out concrete measures in respect of legal capacity and supported decision making for people with intellectual disabilities. It is essential that the new legislation is aligned to the principles of the CPRD.²⁷

Many people with intellectual disabilities will experience mental health difficulties at some point in their lifetime. This is the case for around 50% of people with profound or severe intellectual disabilities and up to 25% of people with a mild to moderate intellectual disability.²⁸ However, there is only one approved centre in Ireland for the treatment of people with intellectual disability experiencing mental health difficulties. Furthermore, there is no unit for the treatment of people with intellectual disability experiencing acute mental health difficulties. People with intellectual disabilities continue to be accommodated in psychiatric units.

A recent inspection report of the Inspector of Mental Health Services of one psychiatric hospital found that the most basic rights of people with intellectual disabilities to dignity and privacy were not protected. One ward accommodating people with intellectual disabilities had no curtains around the beds and no locks on toilet doors.²⁹

Wards of court involuntarily detained in psychiatric hospitals have no right to a mental health tribunal under the provisions of the Mental Health Act 2001.³⁰ The UN Committee on Torture has recommended that Ireland review the Mental Health Act 2001 in order to ensure that it complies with these international human rights standards.

Another area of legislation requiring reform is that pertaining to sexual offences. The Criminal Law (Sexual Offences) Act, 1993 criminalises people with intellectual disabilities. This law makes it an offence to have or attempt to have sexual intercourse with a 'mentally impaired' person unless they are married. This criminalises people with intellectual disabilities who are in consenting sexual relationships but not married. The

²⁷ Essential Principles for Irish Legal Capacity Law, Amnesty International Ireland and the Centre for Disability Law and Policy, National University of Ireland, Galway, 2012

²⁸ Report by the Mental Health Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) to the World Health Organisation, 2000

²⁹ Report of the Inspector of Mental Health Services into St. Senan's Hospital, Waterford, November 2012, Mental Health Commission

³⁰ UN Committee against Torture, Forty-sixth session, 09 May - 03 June, 2011,



same law does not adequately protect people with intellectual disabilities from sexual abuse. The Act excludes sexual offences that fall outside of sexual intercourse or buggery such as oral rape. The Law Reform Commission has said that the law may be incompatible with the European Convention on Human Rights (ECHR).³¹ It is therefore unlikely that it would be compliant with the principles of the CRPD.

The CRPD also places an obligation on governments to guarantee to people with disabilities their political rights and the opportunity to enjoy these rights on an equal basis with others.³² However, there is currently no legislation specifically dealing with the measures required to enable people with intellectual disability to exercise their right to vote.

The CRPD places an obligation on the government to put in place effective legislation and policies to ensure that instances of exploitation, violence and abuse against people with disabilities are identified, investigated and, where appropriate, prosecuted.

Recorded crimes against 'mentally impaired' persons have almost doubled over the past year.³³ The Prohibition of Incitement to Hatred Act, 1989 does not include disability as an aggravating factor. The exploration of violence against people with disabilities as a hate crime should be addressed as part of the implementation plan for the National Disability Strategy. The basic citizenship rights of people with an intellectual disability should be enumerated and advanced.

4.5 Cost of Disability

A cost of disability payment to meet the extra costs associated with a disability has been recommended in numerous reports and studies. In 1996 a cost of disability payment was recommended by the Commission on the Status of People with Disabilities. The National Rehabilitation Board (NRB) subsequently published several papers on the cost of

³¹ Law Reform Commission, 2006, *Vulnerable Adults and The Law*

³² Article 29 UN Convention on the Rights of Persons with Disabilities

³³ Central Statistics Office, *Recorded Crime, Quarter 2 (2012)*, 28 September, 2012



disability.³⁴ In 2002 the Forum of People with Disabilities published a reflection document on a cost of disability payment.³⁵ In 2002 the government established a working group to examine the feasibility of a cost of disability payment.³⁶ This group asked the NDA to undertake research in the area. The NDA subsequently commissioned Indecon to carry out the study, which was published in 2004.

*'The National Disability Authority sees the cost of disability payment as a basic equality issue. The 'cost of disability' can be defined as the amount it costs a disabled person to achieve the same standard of living as a non-disabled person. A Cost of Disability payment would help equalise the cost of living experienced by people with disability, whether they were in employment or not.'*³⁷

More recently, a study into the cost of disability found that addressing the extra economic costs of disability to be 'a logical step towards alleviating elements of social exclusion for people with disability'. The study used the standard of living standard of living approach to estimating the cost of disability. It found that THIS approach 'allows us to quantify, for the first time, the additional long-run economic costs of living associated with disability' and the study concludes that 'the extra economic cost of disability in Ireland is large and varies by severity of disability, with important implications for measures of poverty.'³⁸

The Implementation Plan for the NDS must include a clear and strong commitment that a cost of disability payment will be introduced as a matter of urgency. The current government has committed to examining the issues that arise in regard to the cost of disability after the development of the needs assessment provided for in the Disability Act, 2005.³⁹ This needs to be progressed as a matter of urgency.

³⁴ NRB Cost of Disability Study 1, 1995; NRB Cost of Disability Study 2, 1998; NRB Cost of Disability Study 3, 1998

³⁵ Forum of People with Disabilities, 2002, A Reflection Document on a Cost of Disability Payment

³⁶ Government of Ireland, 2000, Programme for Prosperity and Fairness

³⁷ Speech by Angela Kerins, Chairperson of the National Disability Authority, April 2004, Dublin

³⁸ Cullinan J, Gannon, B Lyons, S., 2011, 'Estimating the extra cost of living for people with disabilities', *Health Economics*, 20: 582–599

³⁹ Towards 2016: Ten-Year Framework Social Partnership Agreement 2006-2016



4.6 Priority Actions for Government Departments

The table below summarises the priority actions for government departments which should be included in the implementation plan for the NDS.

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|---|
| <p>Dept of Social Protection</p> <ul style="list-style-type: none">• Introduce a cost of disability payment• Introduce the Personal Advocacy Service as provided for in the Citizens Information Act 2007• Introduce measures to make available a range of other advocacy supports for people with disabilities |
| <p>Dept of Health</p> <ul style="list-style-type: none">• Introduce personal budget model so that people with intellectual disabilities have the flexibility to make choices that suit their needs best• Develop a clear timeframe for extending the Assessment of Need under the Disability Act 2005• Ensure and monitor the HSE development of a clear, coherent implementation strategy for the four key policy documents which fall under its remit• Ensure and monitor the participation of people with disabilities, and, in the case of children, their parents/carers in the planning, design and delivery of key disability programmes and policies by the HSE (and the structures which replace it) |
| <p>Dept of Justice and Equality</p> <ul style="list-style-type: none">• Introduce measures to remove the barriers by people with disabilities in accessing the justice system• Introduce capacity legislation and systems of supported decision making for people with intellectual disabilities• Publish a programme of legislative reform to meet alignment with the CRPD• Publish a timeframe for ratification of the CRPD |
| <p>Dept of Education and Skills</p> <ul style="list-style-type: none">• Publish a plan for implementation of all sections of the EPSEN Act 2004 |
| <p>Dept of Jobs, Enterprise and Innovation</p> <ul style="list-style-type: none">• Publish a comprehensive employment strategy for people with disabilities |



5. Monitoring and Review

The CRPD places an obligation on the government to ‘promote actively an environment in which persons with disability can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs’ (CRPD, Article 27).

The Implementation Plan for the NDS should include an explicit commitment to actively involve people with disabilities, including children with disabilities, parents, guardians and family members in the monitoring and review of the plan.

Monitoring implementation of the National Disability Strategy should be transparent, inclusive of people with a disability, and should address not only progress made but also review and refocus the content of the plan to ensure continuous improvement

The NDA commented at their national conference on 10 October 2012 that three quarters of the disability budget was expended in areas of service provision that represent institutional and centre-based elements of service. The absence of genuine representation of people with disability and, for children, their family members is a significant barrier to successful implementation of the NDS and to the wider reform programme of intellectual disability services.



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