

Oireachtas Joint Committee on Justice, Defence and Equality Review of the Operation of the Disability Act 2005 and the National Disability Strategy

A Submission by the Citizens Information Board (May 2015)

Introduction

The Citizens Information Board (CIB) considers that the review by the Joint committee of the Operation of the Disability Act and the related implementation of the National Disability Strategy is important and timely and welcomes the opportunity to make a submission on the matter.

The Submission is divided into three main sections. Section One comments on some aspects of the operation of the Act, Section Two comments on the National Disability Strategy and related matters and Section Three makes some general observations deemed relevant to the review.

Role of the Citizens Information Board

The principal functions of the Citizens Information Board (CIB) are to support the provision of and, where appropriate, provide directly to the public, independent information, advice and advocacy services in relation to social services. The CIB is also required to assist and support individuals, particularly those with disabilities, in identifying their needs and options and in accessing their entitlements to social services. In this regard, the Citizens Information Act 2007 provides for the introduction by the CIB of a range of advocacy services, including a Personal Advocacy Service aimed at people with a disability¹. Other functions of the Board are to support, promote and develop: (i) greater accessibility, co-ordination and public awareness of social services; (ii) the dissemination of integrated information in relation to such services by statutory bodies and voluntary bodies and (iii) the provision of information on the effectiveness of current social policy and services and to highlight issues which are of concern to users of those services.

The CIB funds and supports the nationwide network of Citizens Information Services (CISs)² and the Citizens Information Phone Service (CIPS). It also provides and manages the Citizens Information Website (www.citizensinformation.ie).

The National Advocacy Service for People with Disabilities (NAS) is funded and supported by the CIB as is the Sign Language Interpreting Service (SLIS). The NAS provides an independent, confidential and free, representative advocacy service that works to ensure that when life decisions are made, due consideration is given to the will and preference of people with disabilities and that their rights are safeguarded. SLIS is the National Sign Language Interpreting Service for Ireland with the overall goal of ensuring that Deaf people can exercise their rights under equality and disability legislation and access their entitlements to public and social services on an equal basis with others.

¹ The establishment by the Citizens Information Board of the Personal Advocacy Service was deferred by the Government in the light of current budgetary circumstances.

² Citizens Information Services and the Citizens Information Phone Service dealt with over 700,000 callers in 2014 and over a million queries.

National Advocacy Service for People with Disabilities (NAS)³

The NAS was set up by the CIB in 2011 to provide independent, representative advocacy services for people with disabilities. The primary target group for NAS is more vulnerable people with disabilities. NAS has a particular remit to support people with disabilities who are isolated from their community, have communication differences, are inappropriately accommodated, live in residential services, attend day services and have limited informal or natural supports. NAS is person centred, accountable, accessible, impartial and independent of service providers, families and other supports.

Who is using NAS?

The total NAS client numbers in 2014 was 1013 - people with an intellectual//learning disability (43%); people with physical/sensory disabilities (30%); people with mental health difficulties (21%); and people on the autistic spectrum (6%).

While NAS has a particular focus on people in residential services for people with disabilities, it has been noted that to reach the most vulnerable people who do not have the ability to self-refer and who may not have family or other informal supports, NAS relies on the service providers and staff to identify advocacy needs and to make referrals. There is no statutory duty on public bodies or disability service providers to co-operate with NAS advocates. In practice, NAS continues to develop a range of responses to enable advocates to work within institutional settings to support people's involvement in decisions that affect their lives.

Disability Act 2005

Assessment of Need

A core provision of the Disability Act 2005 is the provision of an individual's right to an independent assessment of need for people with disabilities, and a subsequent right to receive necessary social services on the basis of a service statement. Under the Act, people with disabilities are entitled to:

- Have their health and educational needs assessed
- Have individual service statements drawn up setting out what services they will get
- Access independent complaints and appeals machinery
- Avail of services of personal advocates

As implemented, provision has only been made for children born after June 1st 2002 to be eligible to apply for an assessment. It had been envisaged that provisions of the Disability Act dealing with persons between the age of five years and eighteen years would be rolled out in 2010 in tandem with the Education for Persons with Special Educational Needs (EPSEN) Act 2004. It was envisaged that the statutory requirements of Part 2 of the Disability Act would be extended to adults no later than 2011. However, the Government took a decision in October 2008 that it was not possible to implement the legislation at that time due to financial circumstances.

Statutory Time Limits for Assessment of Need

Section 9(5) of the Act states that "the Executive shall cause an assessment of

³ http://www.citizensinformationboard.ie/services/advocacy_services/

the applicant to be commenced within 3 months of the date of the receipt of the application or request and to be completed without undue delay. Timeframes for completion of the assessment and the provision of a service statement are provided for in relevant Regulations.”⁴

“The executive shall complete the assessment and forward the assessment report to the Liaison Officer (for preparation of service statement) within a further 3 months from the date on which the assessment commenced.” Disability (Assessment of Needs, Service Statements and Redress) Regulations 2007/ S.I. No. 263 of 2007.

“The service statement shall be completed within 1 month following receipt of assessment report by the Liaison Officer”, Disability (Assessment of Needs, Service Statements and Redress) Regulations 2007)

The HSE acknowledges that, while overall activity has increased year on year, a significant number of applications are overdue for completion. For example, nationally 775 assessment reports were completed in Q4 2014 and only 36% of these were completed within the timelines as provided for in the regulation.⁵

Another key issue identified relating to assessment of need is that parents of children with a disability have no legal entitlement to support in seeking redress in respect of the assessment of need. This support role was envisaged as being provided by the Personal Advocacy Service. Although the Disability Act states that a person’s health and personal social services will be described in the service statement, the extent to which the health and personal social services they receive is in practice integrated with the assessment of need and related service statement as envisaged in the legislation is problematic. Anecdotal evidence and media reports consistently reference situations where therapies (speech and language therapy, occupational therapy, physiotherapy, psychology services) are not available to children in accordance with assessed needs.

Assessment of Need Complaints Procedure

The Act (Sections 14-20) provides for complaint and appeals procedures in relation to the assessment of need process. A person can make a complaint about a determination by an assessment officer or the way the assessment was conducted. A HSE official (Complaints Officer), will attempt to resolve the complaint informally. However, if this is not possible the complaint will be investigated further and a recommendation will issue to the applicant and the HSE. A person may lodge an appeal to this recommendation. An appeal will be investigated by an independent appeals officer who is appointed by the Minister for Health. A key issue with the complaints system is that the appeals officer’s decision is final and may only be appealed to the High Court on a point of law (Section 20).

Accessible Transport

Section 34 (a) of the Act requires the development of a sectoral plan by the Minister for Transport to include a programme of projected measures for the provision of access to persons with disabilities to passenger transport services for the general public. The Sectoral Plan for Accessible Transport, *Transport Access for All*, (revised in 2012)⁶ sets out the proposals of the Department of Transport, Tourism and Sport and the agencies under its aegis in relation to the rollout of a comprehensive programme of accessible transport. It outlines a series of policy objectives and targets for accessible transport across all modes of transport. It indicates measures to make trains, buses, taxi and hackney services, air and marine transport, and parking facilities more accessible to people with disabilities. It notes

⁴ <http://www.irishstatutebook.ie/2007/en/si/0263.html>

⁵ <http://www.hse.ie/eng/services/publications/corporate/performance-reports/d14par.pdf>

⁶ <http://www.dttas.ie/sites/default/files/public-transport/tafa/secplanen/secplan2013en.htm>

the progress made to date⁷ and refers to progress towards improving transport provision in rural areas as well as measures to increase monitoring and enforcement of existing accessibility provisions are also proposed and possible initiatives to improve the availability and accessibility of travel information available to people with disabilities.

Public transport providers have to a large extent engaged with the challenge of developing accessible services and embarked on a programme of introducing accessible vehicles and rolling stock as well as upgrading the accessibility of railway stations and bus stops. Training in disability awareness and the enhancement of information provision to cater for the needs of people with different types of disability have become strategic elements in each of the main transport agencies.

Despite these developments, the issue of transport accessibility continues to be significant.⁸ There is no low-floor accessible public bus transport in many parts of the country. State-funded local transport initiatives in rural areas are not required to have fully accessible vehicles. Train accessibility for wheelchair users continues to be dependent on ramps being put in place in response to requests from individual passengers. Anecdotal evidence regularly refers to a difficulty in finding out about the availability of accessible bus transport in rural areas.

The issue of accessible taxis has been the subject of much debate over many years. For example, as far back as 2002 an NDA submission to the Department of the Environment and Local Government made a number of recommendations for qualitative improvements in taxi services and the future regulation of those services. Despite increases in the number of accessible taxis, feedback from people with disabilities indicates that it can be extremely difficult to get an accessible taxi in many parts of the country.

Provision of Services by Public Bodies

The Act refers to the provision of services by public bodies and states that where a service is provided to a public body, the head of the body shall ensure that the service is accessible to persons with disabilities (27(1)). However, this requirement does not apply (27 (2)) if the provision of access by persons with disabilities to any services provided would not be practicable or would not be justified having regard to the cost of doing.

The Act also requires public bodies to ensure that “as far as practicable, the contents of the communication are communicated in a form that is accessible to the person concerned” (28 (1)b). The term ‘as far as practicable’ is problematic for the Deaf community and results in some providers maintaining that that they are not required to communicate through, for example, Irish Sign Language.

The term ‘public body’ used in both Article 27 and Article 28 is also problematic from a service user perspective. For example, General Practitioners and in some cases private hospitals/ consultants are regarded as contracting with the HSE to provide services to the public. However, as reported by SLIS, currently, no ISL interpretation is provided in GP or consultant settings. While GPs and local HSE area offices have been approached by SLIS to fund interpreters at GP appointment level, in most cases this has been refused. Also, large hospitals and organisations tender for ISL/English Interpreters through spoken language

⁷All of the Dublin Bus fleet is now composed of low floor wheelchair accessible buses. Progress has been made with the roll out of Real Time Passenger Information systems in the Greater Dublin Area, Cork, Limerick, Galway, Waterford and at Dublin Airport.

⁸ *Transport and Access to Social Services (CIB)*
http://www.citizensinformationboard.ie/downloads/Getting_There_Report_2010.pdf

agencies whose staff may not have an adequate understanding of the complex nature of ISL/English interpreting.

The lack of professional interpreter services in medical settings is regarded by SLIS⁹ as resulting in miscommunication or a lack of communication with potential risks to the health and wellbeing of Deaf individuals. “It is not sufficient to have staff members who may know some sign language or family members translating for Deaf individuals”.

There is a clear need for Public Services to ensure that access for Deaf service users is made easier in accordance with underlying principle of accessibility contained in the Act.

Accessible Information

While there are a number of published guidelines on the provision of accessible information¹⁰, what is less clear is to what extent, these are implemented by public bodies. Another issue of importance is how information is communicated to people with an intellectual disability or with poor literacy skills. There is a clear need for the use of more easy-to-read formats across all public services.¹¹

National Disability Strategy

The aim of the National Disability Strategy is to underpin the participation of people with disabilities in society. In addition to legislation and sectoral plans, this contains a commitment to a multi-annual Investment Programme. The government’s implementation plan for the National Disability Strategy (NDS) sets out a framework to enable government departments to develop policies on meeting their responsibilities under the legislation and putting in place supports for people with disabilities commensurate with need. The organisation of the NDS Implementation Plan’s high level goals around rights for citizens with disabilities, rather than being arranged around departmental responsibilities is important. However, the delivery of services and supports in accordance with such rights clearly requires the allocation of resources centrally and by individual departments and agencies if these goals are to be achieved.

In looking at the NDS, it is important to have cognisance of two factors: (a) the social and policy context has changed considerably since the legislation which comprises the NDS was first published; and (b) key pieces of that legislation remain to be fully commenced.

The policy context relating to people with disabilities has evolved significantly in the past decade. As well as the National Disability Strategy¹², this has included greater emphasis on community-based housing provision, a housing strategy for people with disabilities, individualised funding, person-centred planning, supported decision-making and a new service funding model for the NGO sector proposed in the 2012 Value for Money (VFM) Review of Disability Services.¹³

⁹ See separate SLIS submission to the Oireachtas Joint Committee.

¹⁰ ‘Access to Information for All’ (Citizens Information Board 2009) www.citizensinformationboard.ie/Publications/; National Disability Authority, 2006. ‘Code of Practice on Accessibility of Public Services and Information provided by Public Bodies’: <http://nda.ie/Good-practice/Codes-of-Practice/Irish-Code-of-Practice-on-Accessibility-of-Public-Services-and-Information-Provided-by-Public-Bodies/>

¹¹ For a useful example of an Easy-to-Read publication, see Transport Access for All 2012, Sectoral Plan <http://www.dttas.ie/sites/default/files/publications/public-transport/english/sectoral-plan-accessible-transport-transport-access-all/easy-read.pdf>

¹² This includes the Disability Act 2005, the EPSEN Act; the Citizens Information Board Act 2007; Departmental Disability Sectoral Plans and the National Housing Strategy for People with a Disability 2011-2016.

¹³ http://www.dohc.ie/publications/VFM_Disability_Services_Programme_2012.html

The 2007 UN Convention on the Rights of Persons with Disabilities has provided an important reference point for new thinking in respect of people with disabilities and its provisions are centrally relevant to both the Disability Act and the National Disability Strategy. Article 12 is particularly relevant in that it provides for equal recognition before the law for people with disabilities. It requires that appropriate measures be taken to provide access by persons with disabilities to the support they may require in exercising their legal capacity and to asserting their will and preferences accordingly. The concept of supported decision-making has been progressed significantly in the *Assisted Decision-making (Capacity) Bill 2013*.¹⁴

Sectoral Plans

Six Government Departments were required under the legislation to produce sectoral plans and this was completed in 2006. It is not entirely clear why other departments, in particular, the Department of Education and the Department of Justice and Equality were not required to publish sectoral plans. It is now timely to look again at the requirement to produce and regularly update sectoral plans and to explore the option of requiring all government departments to produce and deliver on such plans.

Comprehensive Employment Strategy

The key commitment to produce a comprehensive employment strategy for people with disabilities has been subject to significant delay. It is reported (Irish Times 26th May 2015) that the Government intends to publish a comprehensive employment strategy for people with a disability within weeks. It is important that this strategy covers all aspects of employment, including employment in sheltered enterprises. Further clarity is required on the legal position of employees in sheltered workshops and the safeguards necessary to protect their rights.

Other Factors Relevant to the Review

Cost of Disability

A Cost of Disability payment was recommended by the Commission on the Status of People with Disabilities in its 1996 report. *Towards 2016* notes that in the context of rationalising existing allowances to people with disabilities, “other issues around the cost of disability will be considered following the development of a needs assessment system provided for under Part 2 of the Disability Act 2005” (p. 68). A 2011 study¹⁵ on 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 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. The study concluded that ‘the extra economic cost of disability in Ireland is large and varies by severity of disability, with important implications for measures of poverty’. The issue of the cost of disability remains a matter of concern.

The Challenge of Providing Resources Commensurate with a Changed Policy Context

Catering for the diversity and multi-faceted needs of the population of people with disabilities poses significant challenges for the exchequer. The new policy and legislative framework that emerged over the past decade has been marked by a more socially inclusive approach to disability which was reflected in new concepts in policy statements, including, in particular,

¹⁴ CIB Submission on Assisted Decision making (Capacity) legislation.
http://www.citizensinformationboard.ie/publications/social/downloads/Submission_Assisted_Decision_Making_Capacity_2013.pdf

¹⁵ Cullinan J, Gannon, B Lyons, S., 2011, ‘Estimating the extra cost of living for people with disabilities’, *Health Economics*, 20: 582–599

the social model of disability, the recognition of 'voice' and self-advocacy ('nothing for us without us'), people with disabilities having the same choice, control and freedom as any other citizen (at home, at work and as members of the community) and the mainstreaming of service provision across the life-cycle. However, the issue of resources is centrally relevant in that if the end-product services are not actually available because of resource constraints, the legislative provisions and more inclusive policy discourse in effect loses much of its impetus. Specifically, the failure to implement the provisions of Part 2 of the Disability Act 2005 which gives people with disabilities an entitlement to an independent assessment of health and education needs and a service statement accordingly is a significant gap. The system for allocating resources as outlined in the Disability Act 2005 relies heavily on governmental discretion and cannot be judicially challenged by a person who has an entitlement to services. Thus, despite these empowering elements of reform at international and national levels, the Irish legislation may not fulfil in practice many of the UN Convention's aspirations.

Enhancing the Role of Advocacy

A cultural and systemic shift is required to transform thinking about people with disabilities as decision-makers in their own right. In a culture and system within which people with disabilities are generally viewed as lacking capacity, with decisions being made "in their best interests" by others, the role of the advocate will continue to be questioned and resisted. For example, NAS reports advocates experiencing resistance in cultural and systemic ways. Progressive change will depend upon a multifaceted response. This must include consideration of the provision of statutory powers to support advocacy. The challenge for the advocate to support the person is complex, often requiring change in an organisational process. Often, in services where an advocacy outcome occurs in relation to one individual, there appears to be no generalised change applied in relation to other individuals in the same situation. These are matters which, while not specific to the Disability Act or the National Disability Strategy, render the proactive implementation of rights-based legislation more difficult.

Review of the Operation of the Disability Act Carried Out in 2010¹⁶

The 2010 Review of the Operation of the Disability Act carried out by the Department of Community, Equality and Gaeltacht Affairs in 2010 provides a detailed account of stakeholder perspectives. These continue to be relevant and will no doubt be considered by the Joint Committee.

¹⁶<http://www.justice.ie/en/JELR/Review%20of%20the%20Operation%20of%20the%20Disability%20Act%202005.pdf/Files/Review%20of%20the%20Operation%20of%20the%20Disability%20Act%202005.pdf>