



**INCLUSION IRELAND**

National Association for People with an Intellectual Disability

**Submission to the Oireachtas Joint Committee on  
Justice, Defence and Equality on the operation of the  
Disability Act 2005**

This document is in font 12 Verdana in line with Inclusion Ireland's plain English guidelines

## **About Inclusion Ireland**

Established in 1961, Inclusion Ireland is the national organisation working for the rights of persons with an intellectual disability. Our membership is drawn from persons with intellectual disability; parents and family members; providers of services to persons with a disability, academics, policymakers and others.

Inclusion Ireland uses a human rights-based approach to its work. This approach recognises persons with an intellectual disability as rights holders with entitlements, and corresponding duty bearers and their obligations. Inclusion Ireland seeks to strengthen the capacities of persons with an intellectual disability to make their claims and of duty bearers to meet their obligations.

## **Introduction**

The passing into law of the Disability Act 2005 followed a long campaign by disabled people, parents and human rights advocates for the introduction of rights-based legislation. The Disability Act 2005 falls significantly short of the rights-based legislative proposals put forward by disabled people. The failure of the Disability Act 2005 to provide for judicial remedy where any of the provisions of the Act are not carried out has been criticised by The Irish Human Rights Commission and the UN Committee on Economic, Social and Cultural Rights.

This submission provides the observations of Inclusion Ireland on the operation of the Disability Act 2005. An emphasis is placed on the operation of Part 2 of the Act, which provides for an assessment of health and education needs of people with a disability. Inclusion Ireland would welcome the opportunity to address the Committee.

## **The assessment of need**

Part 2 of the Disability Act provides for an independent assessment of needs, a related service statement and independent redress and enforcement for people with disabilities.

The Disability 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 Disability Act requires the Health Services Executive (HSE) to appoint assessment officers to carry out or arrange the carrying out of these assessments.

Part 2 of the Disability Act is only partially commenced. As it currently stands, only children born after 1<sup>st</sup> June, 2002 are entitled to apply for an assessment of needs under the Act (regardless of their age at time of application). It was anticipated that the Disability Act would be commenced for children aged between 5-18 years concurrently with the implementation of the relevant sections of the Education for Persons with Special Educational Needs Act, 2004. However, the relevant sections of this law have not been commenced.

## **The statutory timeframe for assessments of need**

It is a requirement under the Disability Act that assessments of need are completed within six months of receipt of an application. According to official figures published by the HSE, 3,361 applications were received for assessments of need in 2011. Only 712 of these applications were completed within the timeframe specified in the legislation.<sup>1</sup>

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<sup>1</sup> HSE, National Service Plan 2012, Supplementary Report, September 2012

At the end of 2013 the average time to complete an assessment of need was nine months. This is significantly longer than the statutory timeframe provided for in the Act.<sup>2</sup>

It has been reported that the HSE has sought to have the statutory timeframe specified in the Disability 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.<sup>3</sup>

Inclusion Ireland regularly deals with calls from parents who are experiencing considerable delays in having their children's needs assessed within the timeframe set out in the Act. One child has been six years in the system for an assessment of needs.<sup>4</sup>

According to HSE figures, 12,650 people awaiting assessment for speech and language therapy. A further 7,908 children are awaiting speech and language therapy treatment.

Parents have told Inclusion Ireland that they have been encouraged not to put their children through the assessment process. There is a significant level of confusion amongst parents. The Ombudsman and Information Commissioner have previously criticised the administration of assessments of need under the Act.<sup>5</sup>

The number of applications for an assessment of need under the Disability Act has increased from 3,505 in 2012 to 4,908 in 2014.<sup>6</sup> There has been no increase in staffing levels to meet this increase in demand. This is contrary to international best practice.<sup>7</sup>

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<sup>2</sup> Assessment of Need Process 4th Quarter 2013 Management Report, HSE, 2013

<sup>3</sup> Major delay in assessing disabled children', Irish Times, Monday, May 7, 2012

<sup>4</sup> Laois Offaly Families for Autism, report on HSE services, 2015.

<sup>5</sup> Speech by Emily O'Reilly, Ombudsman & Information Commissioner, 23 February 2012

<sup>6</sup> HSE Service Performance Report, January 2015.

<sup>7</sup> The Case of Speech and Language Therapy, Inclusion Ireland, 2014

As a result, many HSE areas are completing very few assessments within the statutory timeframes. The table below notes the percentage of assessments completed within statutory timelines<sup>8</sup>. These HSE figures indicate that a person having an assessment completed on time depends on where the person lives.

Date	Total	CHO1	CHO2	CHO3	CHO4	CHO5	CHO6	CHO7	CHO8	CHO9
03/15	39%	84%	89%	64%	20%	35%	62%	25%	59%	15%
01/15	36%	74%	92%	50%	17%	43%	50%	26%	30%	28%

## **Independent redress and enforcement**

Section 16 of the Disability Act 2005 provides for the appointment of a Disability Appeals Officer by the Minister for Health and Children. The Disability Appeals Officer 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 independent Disability Appeals Officer was vacated in December 2011, and remains unfilled.

Under Section 17 of the Disability Act, the Disability Appeal Officer must provide the Minister with an annual report. According to the website of the Office of the Disability Appeal Officer, no annual report has been published since 2011.<sup>9</sup>

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. As it stands, parents of children with a disability have no access to independent complaints, appeal or redress in respect of the assessment of need.

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<sup>8</sup> Derived from HSE Service Performance Reports March 2015 and January 2015.

<sup>9</sup> [www.odao.ie](http://www.odao.ie) accessed 28 May, 2015

## **Assessment of need and advocacy support**

There is very little knowledge of the assessment of need process among parents. Parents would request an assessment sooner if knowledge of the assessment of need was available to them.

“We saw several professionals before anyone mentioned assessment of need. We wasted months. Months are critical when you are talking about a young child with a disability. It seems you have to be lucky to meet the right professional who will flag the assessment of need process to you.”<sup>10</sup>

Many parents of children with an intellectual disability have contacted Inclusion Ireland complaining about the lack of information about the administration of the assessment and inconsistencies with how assessments of need are undertaken. Parents, struggling with the demands of caring for their child with a disability, do not have the necessary support to overcome the bureaucracy of the assessment of need application process.

The Citizens Information Act 2007 provides for a Personal Advocacy Service to be established. One of the key functions of the Personal Advocacy Service is to support or assist people in making applications and appeals in respect of the assessment of need under the Disability Act. However, the Personal Advocacy Service has not been introduced as the section of the Citizens Information Act 2007 has not been commenced.

## **The quality of assessments of need**

The Health Information and Quality Authority (Hiqa) published standards in relation to how the statutory assessment of need should be undertaken. However, there is no systematic national monitoring of compliance with these standards. The Disability Act 2005 contains no

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<sup>10</sup> National Disability Authority (2011)

provision for the monitoring or review of the quality standards developed by Hiqa. As such, there is no information on the quality of assessments.

## **Assessment of need and education**

In 2011, the National Disability Authority (NDA) published a report on the practice of assessment of need under the Disability Act 2005. This report 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 Education for Persons with Special Educational Needs Act, 2004 (EPSEN).

This report also highlights the incompatibility of the assessment of need under the Disability Act 2005 with the resource allocation rules currently operated by the Department of Education and Skills. According to the NDA report, as a result of 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.<sup>11</sup>

This report noted that schools have limited access to assessments for children. However, many school supports for children are based upon a child having a diagnosis.<sup>12</sup>

In the absence of the commencement of the EPSEN Act, schools are directing parents towards the assessment of need under the Disability Act.

“Referrals from the education sector are a huge issue. Teachers think that assessment of need will get them psychology determination that will get the child what they need in school.”<sup>13</sup>

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<sup>11</sup> National Disability Authority (2011)

<sup>12</sup> For example: Circular SP ED 02/05 or Home based July Provision Information Note.

<sup>13</sup> National Disability Authority (2011)

Until such time as the EPSEN Act is fully commenced, children will continue to be directed towards the assessment of need to obtain a diagnosis that will enable them access to educational supports. 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 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 HSE assessment officers.

## **Sectoral Plans under the Disability Act**

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. However, the Disability Act 2005 does not place a requirement on the Department of Education or the Department of Justice and Equality to publish sectoral plans. No sectoral plans have been published since 2006.

## **Conclusions**

There is an inconsistent approach to assessing children under the Disability Act, a failure to commence the relevant section of EPSEN Act and an absence of an independent appeals mechanism. This 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 children at a crucial time in the 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 those who do not qualify on age grounds.

There is no consistency in how assessments are carried out, and there is widespread failure to comply with the statutory timeframe for completing assessments. The independent appeals mechanism has been removed. Failure to introduce the Personal Advocacy Service by commencing the relevant section of the Citizens Information Act, 2007, means that parents have no access to independent advocates to assist them with their applications for an assessment of need under the Disability Act.