## National Disability Authority Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005



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## **Executive Summary**

This project was a partnership between the Department of Health (Office of Disability and Mental Health), the Health Service Executive (National Disability Unit) and the National Disability Authority.

The purpose of this report is to inform the operation of the statutory assessment of need process under the Disability Act 2005.

The overall aims of this report were:

- to describe practice and understandings of various personnel involved in the statutory assessment of need<sup>1</sup>
- to understand parents' understandings, motivations and experiences of the statutory assessment of need process

There is significant variation in the number of applications for a statutory assessment of need in different Local Health Office areas. There is also significant variation in Local Health Office areas in the number of assessments of need completed within the statutory timeframes. Such variation can only be explained by reference to a wide range of factors.

Prior to this report there was no published material which looked at the issues of operating the statutory assessment of need process across more than one Local Health Office area. There was also little published information addressing questions, such as:

- How the statutory assessment of need process operates in practice?
- What contributes to the variation in how the statutory assessment of need process operates in different locations?
- What are the obstacles to ensuring that more statutory assessments of need are completed within statutory timeframes?

The fieldwork undertaken for this report sought to address these operational, organisational and process issues. This report is not a review of the clinical practice of those who assess children as part of the statutory assessment of need process.

The findings of this report highlight challenges that have emerged in operating the statutory assessment of need process. It also highlights some good practice and innovations that have been developed to meet the needs of young children and families which are in keeping with the legal requirements of the Disability Act.

<sup>&</sup>lt;sup>1</sup> This report did not consider the role of Liaison Officers. The Liaison Officer role is prescribed under the Disability Act 2005 but this report looked at the statutory assessment process under the Act whereas the Liaison Officer role relates to providing for service delivery.

The main findings of this report are based on the views of those who were interviewed for this project. These include:

- in the absence of the commencement of relevant sections of the Education for Persons with Special Education Needs Act 2004 the Disability Act 2005 is being used as means to expedite special education assessments
- areas where early intervention services and / or children's services have been integrated are better equipped to meet the demand for assessment under Part 2 of the Disability Act
- assessors are extremely mindful of the resource allocation or service eligibility rules of the health and education systems from which parents are seeking supports. Such rules play a critical role in driving a diagnostic approach to assessments that assessors conduct as part of the statutory assessment of need
- factors which contribute to assessors developing a greater "comfort zone" around the language of the Part 2 of the Disability Act are:
  - integrated or coordinated service delivery structures
  - working as part of a multi-disciplinary team
  - receiving some ongoing mentoring on the requirements of the statutory assessment of need
- health and education professionals, rather than parents or guardians, are in practice responsible for referrals to the statutory assessment of need process
- the current operation of the statutory assessment of need process does not require that **all** children with a disability receive an assessment of need. An unintended consequence of this is that the statutory assessment of need process can be used as a means to circumvent existing waiting lists for assessments. In this way it has, in some locations, created a "two-tier" system for entering services
- there is a great deal of variation in how long assessors take to conduct statutory
  assessments of need. However, individual assessors contribute the same number of
  person hours to conducting statutory assessments of need as they do to other
  similar assessments that they conduct
- many assessors remain unclear as to what is required of them under Part 2 the Disability Act 2005. While some regional training sessions have been conducted and national guidance has been produced, many assessors have received very little guidance from their local managers on the requirements of the Disability Act 2005 and the vast majority assessors receive no feedback on the assessments that they conduct under the Disability Act 2005
- parents are mostly positive about their experience of the statutory assessment of need process. Parents' satisfaction, however, is related to whether or not their child received services or enhanced services after the statutory assessment of need process was completed

The findings do not indicate that there is one single solution which will resolve all the challenges to operating a statutory assessment of need. Rather they suggest that a

number of interdependent changes would allow for a more efficient statutory assessment of need process. The concluding remarks of this report identify a number of key interdependent issues which require consideration. These include:

- developing a mechanism, such as a legal instrument, to bring greater clarity as to what is in fact legally required of assessors
- integrating early intervention and children's disability services. This is happening for other reasons but it should significantly reduce the incompatibility of the requirements of the statutory assessment of need process and resource allocation and service eligibility rules
- providing assessors with feedback and ongoing mentoring on the requirements of statutory assessment of need process
- facilitating engagement between Department of Health and Department of Education and Skills on specific issues, and in particular on the issue of the incompatibility of the statutory assessment of need process and the resource allocation rules operated by the Department of Education and Skills. In particular, the implementation of the recommendation of the National Council for Special Education research report that, "a diagnosis should not be a prerequisite or determinant for the allocation of additional resources for a child or young person with SEN" should be advanced. Given the critical importance of the interface between health and education services for young children with disabilities and/or special education need, the National Disability Authority advises that a Task Force, reporting to both the Minister for Health and the Minister for Education and Skills, be established to look at these issues and requested to report within as short a timeframe as is appropriate.

## I. Introduction and context

This section sets out the background to the statutory assessment of need process, including its legislative underpinnings.

### I.I Legislative context

### I.I.I National Disability Strategy

The National Disability Strategy was launched in September 2004. The Strategy comprised of four elements:

- The Disability Act 2005
- Sectoral Plans for six Government Departments<sup>2</sup>
- Comhairle (Amendment) Bill 2004<sup>3</sup>, including a commitment to a Personal Advocacy Service
- A Multi-Annual Investment Programme for disability support services(2005-2009)

The Strategy built on existing policy and legislation including Equality legislation and the Education of Persons with Special Educational Needs Act 2004 and the policy of mainstreaming service provision for people with disabilities within the State agencies that provide the service to citizens generally.

### I.I.2 Disability Act 2005

The Disability Act 2005 provided a legal underpinning for the government's existing policy of mainstreaming by placing obligations on public bodies in relation to:

- Access to public buildings, services and information for people with disabilities
- Ensuring that services and information is accessible to people with disabilities
- A complaints mechanisms, in the form of appeals to the Ombudsman, for people with difficulties accessing public services
- Employment targets for people with disabilities in the public sector
- Integration of services to people with disabilities with those of persons without disabilities

<sup>&</sup>lt;sup>2</sup> The Six sectoral plan Departments are: Health (previously Health & Children), Social Protection (previously Social and Family Affairs), Transport, Tourism and Sport (previously Transport) Environment, Community and Local Government (previously Environment, Heritage and Local Government), Communications, Energy and Natural Resources (previously Communications, Marine and Natural Resources), Jobs, Enterprise and Innovation (previously Enterprise, Trade and Employment)

<sup>&</sup>lt;sup>3</sup> The relevant aspects of the Comhairle (Amendment) Bill 2004, namely the provisions for a personal advocacy service, were included in the Citizens Information Act 2007

### I.I.3 Part 2 of the Disability Act 2005

In addition to the mainstreaming requirements placed on public sector bodies, the Disability Act 2005 also established a right to an assessment of need.

Part 2 of the Disability Act 2005 provides for a statutory assessment of need process. People who are of the opinion that they might have a disability (or certain others on their behalf) have the right to:

- apply for an assessment of individual needs, which is carried out without regard to the cost of or the capacity to provide service identified in the assessment
- a related service statement
- access to an independent redress and enforcement process

Part 2 of the Act was commenced for children under the age of 5 years on the 1st of June 2007. It was intended that Part 2 of the Act would be progressively commenced for older age groups. In October 2008 further implementation of the Act was deferred as a result of the decision not to commence elements of the Education for Persons with Special Needs Act 2004 and with no alternative timescales for full implementation of Part 2 of the Act having been developed.

As a result of a High Court Case<sup>4</sup> the Health Service Executive have, in effect, been treating all children born after the 1<sup>st</sup> of June 2002 as eligible to apply for an assessment under Part 2 of the Disability Act.

### Right to an assessment

Any person or a parent/guardian, who considers that his or her child may have a disability, is entitled to apply for an assessment of need under the Disability Act. Each Local Health Office area area has a named assessment officer who is responsible for arranging that these assessments take place.

Assessments under the Disability Act 2005 are meant to be undertaken without regard to cost or the capacity to provide any services identified in the assessment. The person concerned or the parent or guardian in the case of a child will be given an Assessment Report, arising from a statutory assessment of need.

### **Definition of disability in Part 2 of the Disability Act 2005** The Disability Act 2005 defines disability as follows:

"disability", in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by

<sup>&</sup>lt;sup>4</sup> High Court 2009 – Record Number 148/MCA (Dykes vs. the Health Service Executive) http://www.odao.ie/judgements/judgement\_20091208.pdf

reason of an enduring physical, sensory, mental health or intellectual impairment

The definition of "disability" in Part 2 of the Disability Act is a person with a "substantial restriction" which—

(a) is permanent or likely to be permanent, results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes, and

(b) gives rise to the need for services to be provided continually to the person whether or not a child or, if the person is a child, to the need for services to be provided early in life to ameliorate the disability.

### Assessment report and service statement

The assessment report will indicate:

- whether a person has a disability
- the nature and extent of the disability
- the health and education needs arising from the disability
- the services considered appropriate to meet those needs and the timescale ideally required for their delivery
- when a review of the assessment should be undertaken

In relation to the assessment of education needs under the Disability Act, the Guide to the Disability Act 2005 indicates that Part 2;

"establishes a system for the assessment of individual **health service needs** and where appropriate the **education needs** for persons with a disability **over the age of 18**"<sup>5</sup>

Where a person is deemed to have health needs occasioned by their disability the assessment report is forwarded to a case manager<sup>6</sup> in the Health Service Executive who will prepare a service statement.

### The **service statement** will outline:

- The health services which the person with a disability will be provided with
- The location(s) where the health service will be provided
- The timeframe within which they will be provided

<sup>&</sup>lt;sup>5</sup> Department of Justice, Equality and Law Reform, 2005, Guide to the Disability Act (emphasis added); http://www.justice.ie/en/JELR/DisabilityAct05Guide.pdf/Files/DisabilityAct05Guide.pdf

<sup>&</sup>lt;sup>6</sup> The Health Services Executive recruited Case Managers and appointed them as Liaison Officers under the Disability Act 2005

- The date from which the statement will take effect
- The date for review of the provision of services specified in the service statement
- Any other information that the liaison officer considers to be appropriate including the name of any other public body to which the assessment report has been sent

### Timelines for the statutory assessment of need process

Part 2 of the Disability Act 2005 and regulations published subsequently establish the following timeframes for which various stages of the statutory assessment of need process must be completed:

- Acknowledgement of an application for an assessment of need under the Act must take place within 14 days of receipt of the application
- The assessment must be commenced without undue delay or within three months of the application being received
- The assessment will be completed and forwarded to the Liaison Officer without undue delay or within three months from the date on which the assessment was commenced

### Appeal mechanisms

Sections 16 to 23 of the Act provide for an independent appeals system which allows a person to appeal against a finding or recommendation under section 15(8) of the Act or against the non-implementation by the Health Service Executive or the head of an education service provider of a recommendation of a Complaints Officer. The Health Service Executive is required to have in place designated Complaints Officers. A permanent, independent Disability Appeals Officer, as provided for in Part 2 of the Act, was established by the Department of Health on the 1st June 2007. Complaints not resolved by the Health Service Executive Complaints Officer can be subject to appeal to the Disability Appeals Officer. Ultimately, a person may take their appeal to the Ombudsman.

### Reports under Section 13 of the Disability Act 2005

Section 13 of the Disability Act requires that the Health Service Executive shall **keep** records for the purposes of:

- identifying persons to whom assessments or services are being provided under Part 2 of the Disability Act 2005 or the Education of Persons with Special Educational Needs Act 2004
- identifying those services and the persons providing the services
- specifying the aggregate needs identified in assessment reports which have not been included in the service statements
- specifying the number of applications for assessments made and the number of assessments completed under that section
- specifying the number of persons to whom services identified in assessment reports have not been provided

- including the ages and the categories of disabilities of such persons
- planning the provision of those assessments and services to persons with disabilities

Section 13 of the Disability Act 2005 requires the Health Service Executive to produce a **report** for the Minister of Health six months after the end of each year, in relation to the aggregate needs identified in assessment reports prepared including an indication of the periods of time ideally required for the provision of the services, the sequence of such provision and an estimate of the cost of such provision<sup>7</sup>

Three reports reflecting data relating to the second half of 2007; 2008 -2009 and 2010 have been published to date<sup>8</sup>. These reports have captured data on the number of applications for statutory assessments of need, the number of statutory assessments of need conducted and the most frequently required services highlighted in the statutory assessment of need reports. However, the two most recent reports have not captured the shortfall in services identified by Section 13 data."<sup>9</sup>. A new methodology introduced at the beginning of 2011 by the Health Service Executive<sup>10</sup> may mean that the report on the 2011 data (to be published in 2012) will be able to report on the gaps between the services identified in the aggregate service statements and the levels of services that children with service statements are estimated to actually require.

### 1.1.4 Education of Persons with Special Educational Needs Act 2004

The commencement of Part 2 of the Disability Act for school-aged children was intended to be introduced in parallel with the commencement of relevant sections of the Education of Persons with Special Educational Needs Act 2004. This Act provided

http://www.hse.ie/eng/services/Publications/services/Disability/2005actreport.pdf

<sup>&</sup>lt;sup>7</sup> Government of Ireland, 2005, Disability Act 2005, section 13 (2); http://www.oireachtas.ie/documents/bills28/acts/2005/a1405.pdf

<sup>&</sup>lt;sup>8</sup> Health Service Executive, 2011, Report to the Minister for the Disability, Equality, Mental Health and Older People at the Department of Health as provided for under Section 13 of the Disability Act 2005 - In Respect of the Data Collected in 2010 http://www.hse.ie/eng/services/Publications/services/Disability/discbilityact2005inrespectdata2010.pdf

Health Service Executive, 2010, **Report to the Minister for the Equality, Disability, Mental** Health At the Department of Health and Children as provided for under Section 13 of the Disability Act 2005 - In Respect of the Data Collected in 2008 and 2009 http://www.hse.ie/eng/services/Publications/services/Disability/rptimpdisact2005.pdf

Health Service Executive, 2009, Report to the Minister for the Equality, Disability, Mental Health as provided for under Section 13 of the Disability Act 2005:- In Respect of the Data Collected in 2007

<sup>&</sup>lt;sup>9</sup> The report on the 2007 data did indicate the shortfall in services identified for those who had received service statements. However, this was based on just over 70 completed statutory assessment of need. A management information system was not in place to capture this information so in 2008 – 2010 this information was not reported on.

<sup>&</sup>lt;sup>10</sup> The means by which this information is captured and aggregated is described in an appendix to the report on the 2008- 2009 data.

for a right to an assessment of education needs, the development of an Individual Education Plans and an independent appeals process.

It had been intended to have the Disability Act 2005 and the EPSEN Act 2004 fully implemented during 2010 in respect of children/young people between 5 and 18 years of age, however, further implementation of the two Acts was deferred in 2009. This included the provisions relating to assessment of special educational need and statutory Individual Education Plans.

The Education of Persons with Special Educational Needs Act 2004 defines a child with special educational needs as a child with 'an enduring physical, sensory, mental health or learning disability or any other condition' which restrict the child's capacity to 'participate in and benefit from education'.

The National Council for Special Education's implementation plan for the Education of Persons with Special Educational Needs Act 2004 proposed a three staged model of assessment and provision for the education of persons with special educational need. The first two stages were to be conducted by schools with the support of the National Educational Psychological Service. The third stage would be a statutory, multi-disciplinary assessment for those children who had an insufficient assessment at stages one and two.

# 1.1.5 Interaction between the Disability Act 2005 and the Education of Persons with Special Educational Needs Act 2004

The design of Part 2 of the Disability Act and the Education of Persons with Special Educational Needs Act 2004 was intended to allow for joined up assessment and service delivery between health and education funded services. If both Acts were fully commenced it would facilitate education authorities to request input from health authorities when conducting assessments and vice versa. This would allow for a coordinated assessment of health and personal social service and education support needs.

Broadly speaking the responsibilities of the health and education sector under the two Acts (when fully enacted) would be:

### **Education sector**

- to assess and meet the special education needs of children with disabilities or conditions which restrict their capacity to participate in and benefit from education
- Special Education Needs Organisers respond to requests from assessment officers when an educational need is identified in the course of an assessment of need under the Disability Act 2005

### Health sector

• to carry out a statutory assessment of need of a child who is not a student who may have special educational needs

- to contribute to the assessment of health and education needs of a student who qualifies under the Education of Persons with Special Educational Needs Act 2004
- to provide the health services necessary for the student to participate in education

As mentioned above, the relevant provisions relating to the right to an assessment of special education need in the Education of Persons with Special Educational Needs Act 2004 have not been commenced. The only statutory right to an assessment of need process available to parents of a child with a disability is an assessment under the Disability Act 2005.

To ensure that schools do not advise parents of children who have education but not health related needs to seek assessment under the Disability Act 2005 the Department of Education and Skills issued a circular in 2011 which sought to clarify that children whose needs related only to participation in school should not ordinarily be advised to apply for an assessment under the Disability Act 2005.

"Where a child under the age of 5 presents as having learning and or behavioural emotional or social difficulties in school, teachers should follow the approach to assessment and intervention outlined in the **National Educational Psychological Service's Continuum of Support Guidelines** to address those needs in the first instance".<sup>11</sup>

### 1.2 Assessment of need standards and guidance

## **1.2.1** Health Information Quality Authority (HIQA) Standards for Assessment of Need

The interim Health Information Quality Authority developed standards, under section 10 of the Disability Act 2005, for the statutory assessment of need process, which were subsequently adopted by the Health Information Quality Authority. The six standards are:

- **Person centred approach** that the person being assessed is involved in the assessment process, that their views of what is important to them are taken into account, that the assessment process is tailored to the individual
- **Information** information on the assessment of need process is widely available and that it is clear and accessible

<sup>&</sup>lt;sup>11</sup> Department of Education and Skills, 2011, Circular No. 0020/2011- Circular to the Management Authorities of National Schools on the Assessment of Need process under the Disability Act 2005; http://www.education.ie/servlet/blobservlet/cl0020\_2011.pdf

- Access to assessment of need assessment of need is easy to access, responsive to the needs of those requiring the service and conducted in a timely manner
- Involving appropriate education and health staff in the assessment of need process staff engaged in the assessment of need process will be competent and that appropriate management and on-going training practices are in place
- **Co-ordinated assessment of need** professionals are involved in the assessment of need, they work in a co-ordinated way
- **Monitoring and review** standards are monitored by Health Information Quality Authority <sup>12</sup>. The contracting agency ensures compliance with the standards and providers conducting assessments conduct regular evaluations of their compliance

**1.2.2 Guidance for assessment of need under the Disability Act 2005 Guidance for Assessors and Assessment Officers Process and Practice Guidelines** were developed by an assessment of need Process Health Service Executive's Working Group in 2009. This working group engaged with the relevant professional bodies of the clinicians involved in the statutory assessment of need process. This guidance sought to:

- provide some principles underpinning statutory assessments of need
- propose a three stage pathway for statutory assessments of need
- provide guidance on the interpretation of some of the terms used in Part 2 of the Disability Act 2005

### Principles underpinning statutory assessments of need

The principles underpinning statutory assessments of need are that they should be:

- Child and family centred the assessment of need should be focused around the child family, recognising them as individuals and concentrating on outcomes that are important to them
- Information and communication information should be available in a timely manner throughout the process, and assessors should engage with the family on the process and arranging assessments
- **Co-ordination** where more than one assessor is involved they should coordinate their assessments
- Outcome-focussed and strengths/needs-based the purpose of the assessment of need is to identify the needs of the child's function in the different areas of development and their ability to participate

<sup>&</sup>lt;sup>12</sup> It should be noted that the Health Information Quality Authority **does not in fact monitor compliance with these standards** and has indicated that it has no immediate plans to commence doing so.

• **Appropriateness of assessment** – the assessment should be appropriate for each individual child and family at this time of assessment, including consideration of age of the child, culture, presenting difficulties and readiness of the whole family

The three-stage assessment proposed in the Guidance for Assessors and Assessment Officers Process and Practice Guidelines The three stage pathway proposed in the guidance involved:

### I. The initial planning stage

The assessment officer should clarify with assessors the specific aim and purpose of assessing this child, following which the team / assessors identify what is required to give a picture of this particular child's health needs, guided by what is normally accepted as good practice in assessment when a child is coming into their service.

### 2. The actual assessment process

An initial clinical interview by one of the team / assessors with the family will gather further information; after which, assessors interact with the child using formal and/or informal assessments either jointly or individually to form an opinion of the child's strengths and needs. Clinicians are the best qualified and best placed to make the decisions, based on their clinical expertise, about the appropriate methods to use and the extent of assessment needed in order to identify the health needs of the child and the services required.

Assessors agree whether a sufficient picture of the child's needs has been gathered at this time or if further assessment is required<sup>13</sup>

### 2. Compilation of the report

All assessors involved in the assessment of need process share outcomes and agree joint recommendations and goals. This information will have been shared already with the parents throughout the process.

Interpretations of terms used in Part 2 of the Disability Act 2005 As some of the language of the Disability Act, 2005 would not have been language that assessors (therapists / clinicians) would necessarily have used the **Guidance for Assessors** sought to give some guidance on the interpretation of some of the terms used in the definition of disability in Part 2 of the Act. So, for example, the term "enduring" was interpreted to mean "likely to last for 12 months or more". The **Guidance for Assessors** is attached in Appendix 4.

<sup>&</sup>lt;sup>13</sup> An extension to the timeline for the assessment process may be negotiated through the assessment officer or an appropriate date for a formal review of the Assessment Report may be specified. Significant assessments which will identify needs should be conducted under the Act through the Review procedure rather than included in the Service Statement. Any assessments not necessary for identification of needs (e.g. diagnostic assessment in some cases) may be included in the Assessment Report and arranged as part of the Service Statement.

## **I.3 Operationalisation of Part 2 of the Disability Act**

### **1.3.1** Experience to date of operating Part 2 - quantitative evidence

Part 2 of the Disability Act 2005 was commenced for children under five years of age in June 2007. In 2007 there were 1,138 applications for a statutory assessment of need, of which 72 were completed in 2007. The numbers of those who have applied and received a statutory assessment of need in the years 2008 to 2010 are shown below in table 1. Table 2 below provides details of the national performance indicators on meeting the statutory timetables for the years 2009 – 2011.

	2008	2009	2010
	2000	2009	2010
Application received	2,535	2,525	3,100
Applications commenced stage 2*	2,279	2,367	2,754
Assessment reports direct to applicant**	152	274	308
Assessment reports to liaison officer***	432	I,663	2,073

## Table I - Numbers applying and receiving statutory assessments of need2008 - 2010

Source: Health Service Executive - Section 13 Reports 2008-2009 and 2010 \*

\* "Stage 2" is the actual assessment of need as opposed to the previous information gathering phase in which the assessment officer collects relevant information

\*\* "Assessment reports direct to applicant" means in effect that the assessment is not being forwarded to the liaison officer as the applicant does not have a disability as defined by the Disability Act 2005

\*\*\* "Assessment reports to liaison officer" means that the person does have a disability as defined by the Disability Act 2005 and that the assessment report has been forwarded to the liaison officer in order that s/he prepare a service statement

	Applications	Started Stage 2*	Reports Completed	Milestone Activity (Throughput)	Assessments Overdue for Completion
2011 to					
the end of					
June	1818	1509	1592	4919	766
2010					
January to					
December	3100	2754	2461	8315	874**
2009					
January to					
December	2525	2367	1937	6829	885***

Source: Health Service Executive

\* "Stage 2" is the actual assessment of need as opposed to the previous information gathering phase in which the assessment officer collects relevant information

\*\* and \*\*\* Assessment overdue for completion figures capture the number of assessments overdue as the end of December for the relevant year.

The number of requests for statutory assessments of need rose by 23% from 2008 to 2009. If the number requests for statutory assessments of need in the second half of 2011 is the same as the number for the first half, the 2011 figure will be 17% higher than the 2010 figure.

There are significant differences within Local Health Office areas. The number of applications for a statutory assessment of need in 2010 ranged from 11 in one Local Health Office area to 179 in another. The number of overdue statutory assessments of need in 2010 ranged from 0 in one Local Health Office area to 242 in another. <sup>14</sup>

As table 3 below shows Autism, primary speech and language, and "no category at this time"<sup>15</sup> represent nearly 60% of the disability categories of the children assessed under the statutory assessment of need. The categories of "physical", "sensory" and "intellectual" combined only account for 6.5% of those coming through the assessment of need process.

<sup>&</sup>lt;sup>14</sup> Health Service Executive, 2011, **Report to the Minister for the Disability, Equality, Mental** Health and Older People at the Department of Health as provided for under Section 13 of the Disability Act 2005 - In Respect of the Data Collected in 2010 http://www.hse.ie/eng/services/Publications/services/Disability/discbilityact2005inrespectdata2010.pdf

<sup>&</sup>lt;sup>15</sup> Discussion with the Health Service Executive indicate that there are often good reasons why "no category a t this time" is listed as the category as it may not be appropriate or practical for assessors to provide a disability category for children in some circumstances.

Table 3 - Category of disability of children whose statutory assessment of			
need reports were completed in the first 9 months of 2011 <sup>16</sup>			

Category of Disability	Numbers	%
Attention Deficit Hyperactivity Disorder	46	2.0%
Autistic Spectrum Disorder	372	15.5%
Global Developmental Delay	110	4.5%
Intellectual	60	2.5%
Mental Health	82	3.5%
No category specified at this stage	437	18%
None	248	10%
Physical	85	3.5%
Primary Speech and Language	595	25%
Sensory	4	0.5%
Specific Learning Disability	53	2.0%
Multiple	305	13%
Total	2407	100%

Source: Health Service Executive

Note I: Applicant with more than one recorded disability appear in the "multiple category"

Note 2: The overall figure of 2407 included 372 or 15.5% of applicants who were deemed not to have a disability as defined in Part 2 of the Disability Act 2005. The National Disability Authority notes that this figure of 372 did not correspond to the "none" category in the table above. The National Disability Authority sought clarity on this issue and were informed by the Health Services Executive that some children (124 children in the case of the 9 months coved by the table above) who are deemed not to have a disability as defined in Part 2 of the Disability Act 2005 are captured in categories other than "none".

### **1.3.2 Experience to date of operating Part 2 - qualitative evidence**

There is very little published information on how the statutory assessment of need process has been implemented and operated across different Health Service Executive Local Health Office areas or by different organisations within those areas. There is also very little information in the public domain about how both families and professionals have experienced the statutory assessment of need process.

The material quoted below does not provide a comprehensive picture of stakeholders' views on the operation of the statutory assessment of need process. It is only quoted as it provided a context for the design of this study, and in particular, for the formation of the questions which were asked of professionals<sup>17</sup> and of parents as part of this study.

<sup>&</sup>lt;sup>16</sup> Data in this table is based on the first three reporting quarters of the Health Service Executive, which run from beginning of January to the end of September 2011.

<sup>&</sup>lt;sup>17</sup> The questionnaires used to interview professionals are contained in appendices 2 and 3 of this report

The Review of the Operation of the Disability Act, 2005 carried out by the Department of Community, Equality and Gaeltacht Affairs<sup>18</sup> observed that:

"General observations in relation to this Part [Part 2] have suggested that discrepancies in interpreting the legislation in relation to it have resulted in a varied approach to rolling it out at local level, resulting in an increased demand for assessments and diminished resource availability to provide interventions"<sup>19</sup>.

Staff views of the statutory assessment of need process are summarised below. These points are based on a very small number of published reports<sup>20</sup>, which are based on the experience in one area at one point in time and need to be read as such.

Negative views expressed on the statutory assessment of need process:

- It is a time consuming process
- It results in additional workload and increased paper work
- Has resulted in assessment being prioritised over intervention
- Has resulted in a delay between referral and access to services
- It results in inappropriate referrals and the prioritisation of children with lesser needs
- Has resulted in an assessment "bottleneck"
- Unclear, ambiguous language is used in statutory assessment of need process
- Extra resources to deal with statutory assessment of need process are not available
- Parents typically do not understand statutory assessment of need process will not result in extra services for their child

Positive views expressed on statutory assessment of need process:

- Has resulted in a standardised approach to assessment
- Provides easier access to an assessment
- Children do receive a comprehensive assessment

<sup>&</sup>lt;sup>18</sup> The Disability Policy Division which conducted this review is now located in the Department of Justice and Equality

<sup>&</sup>lt;sup>19</sup> Department of Community, Equality and Gaeltacht Affairs, 2010, **Review of the Operation of the Disability Act 2005**;

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

<sup>&</sup>lt;sup>20</sup> Muldoon, B. & Coughlan, B., 2009, 'Early intervention services: a survey of parental attitudes toward service provision and impact of the disability act (2005)', **Frontline** (77); Payne, C. & Coughlan, B., 2010, 'Early Intervention: the experiences of staff of the assessment of need in early intervention services)', **Frontline** (79); Enable Ireland North East Services, 2009, 'Enable Ireland Early Intervention Services in the North East', **Frontline** (77)

- It has resulted in improved consistency in report writing among professionals
- It has resulted in better sharing of information among professionals

The Assessment of Need Process Health Service Executive's Working Group brought professionals from different disciplines working in different geographic locations to discuss the operation of the Disability Act.<sup>21</sup>

Assessors' views on the operation of the Disability Act included such views as:

- Some parents want a diagnosis as they perceive this will lead to more resources particularly in education sector
- Legal definition and clinical definition of disability are different
- Timeframes for the statutory assessment of need process may not be ideal for all children and all families
- Clinicians not comfortable stating that a young child has a disability

Little is known about the experiences of children and/or families that have gone through a statutory assessment of need process. Available literature suggests that:

- Children referred via the statutory assessment of need process do not receive any more service than children referred by other routes
- The majority of parents using early intervention services are aware of their right to a statutory assessment of need, but are typically made of aware of this right by health professionals

### 1.3.3 Restructuring of early intervention and children's disability services

Early intervention services and children's disability services have been undergoing a process of change separate from the changes brought about by the roll out of the statutory assessment of need process. However, this restructuring process is a key part of the context in considering the statutory assessment of need process.

Early intervention services have been developing in Ireland since the late 1970s. Services evolved differently within different locations and between different organisations over the next two decades in the absence of a national policy<sup>22</sup>. From about 2000 onwards there was a realisation in some areas that this evolution had resulted in "fragmented services" from the point of view of the child or family with a disability.<sup>23</sup>

<sup>&</sup>lt;sup>21</sup> The Assessment of Need Process Working Group, 2009, Report of the AON Consultation Day, 8<sup>th</sup> of December 2008

<sup>&</sup>lt;sup>22</sup> Individual Health Boards approached the development of early intervention quite differently from each other.

<sup>&</sup>lt;sup>23</sup> For a brief discussion of negotiating a transition from fragmented services to more integrated services in one Local Health Office area see for example, Cuffe, C., 2009, 'Real Partnership Works' Frontline (75)

Efforts have been made to "integrate" different element of early intervention services and / or children's services into a service which is more streamlined from the point of view of the service user. Monies made available under the **National Disability Strategy** (Multi-Annual Investment Programme 2005 - 2009) were invested, in part, in early intervention services. In some areas this investment, and an awareness of the need to prepare for the statutory assessment of need process under the Disability Act, further spurred the integration process. At present the service configuration of early intervention and children's disability services around the country varies:

The configuration of these varies between Local Health Office areas, with some areas having a number of disability specific services largely provided by non-statutory service providers, and others having generic teams looking after the needs of all children regardless of their disability. Some of these generic teams are employed solely by the Health Service Executive, others solely by a non-statutory agency, and some have employees from both the statutory and non-statutory service providers and work in an interagency partnership.<sup>24</sup>

The Health Service Executive recognises that this variation has resulted in a situation where, "some children and their families have little or no access to services".<sup>25</sup>

The Health Service Executive approved a report in 2010 recommending a greater role for primary care in meeting the needs of children with disabilities and also recommended a more integrated structure for specialist school-aged disability resources. A working group has been set up to implement the reports findings. This programme, known as the **Progressing Disability Services for Children and Young People<sup>26</sup>,** "aims to build integrated, geographically based Early Intervention and School-Age Teams providing one clear pathway for all children and young people with disabilities". A resource mapping exercise is currently underway and regional and local implementation structures are being established.

http://www.hse.ie/eng/services/Publications/services/Disability/discbilityact2005inrespectdata2010.pdf

<sup>&</sup>lt;sup>24</sup> Health Service Executive, 2009, **Report of the National Reference Group on Multidisciplinary Disability Services for Children aged 5-18** 

<sup>&</sup>lt;sup>25</sup> Health Service Executive, 2011, **Report to the Minister for the Disability, Equality, Mental** Health and Older People at the Department of Health as provided for under Section 13 of the Disability Act 2005 - In Respect of the Data Collected in 2010

<sup>&</sup>lt;sup>26</sup> The Progressing Disability Services for Children and Young People programme was officially launched in April 2011.

# 2. National Disability Authority's project on the operationalisation of Part 2 of Disability Act 2005

## 2.1 Purpose of National Disability Authority's report

The purpose of this report is to inform and bring added value to the statutory assessment of need process under the Disability Act 2005. The report sets out to highlight good practice and innovations that have been developed to date to meet the needs of young children and families and which are in keeping with the legal requirements of the Disability Act.

Based on the above, the overall aim of this report is:

- to describe practice and understandings of various personnel involved in the statutory assessment of need process across a broadly representative sample of Local Health Office areas
- to understand parents' understandings, motivations and experiences of the statutory assessment of need process

## 2.2 Methodology

A critical success factor for delivering on this project was that professionals involved in the statutory assessment of need process shared their experiences and knowledge of the operation of the statutory assessment of need process in an open and honest manner, provided access to relevant material and provided facilities to enable the National Disability Authority to conduct face to face interviews. In each of the selected Local Health Office areas the National Disability Authority met with and interviewed separately:

- Assessment officer
- Service manager / team leader as appropriate
- Assessors (minimum of three assessors to be met separately)

Interviews lasted up to an hour and half each. For practical reasons the National Disability Authority conducted all the face to face interviews in a given location over the course of a single day. (See Appendix I for the interview schedule).

The National Disability Authority also requested that assessment officers identify and make contact with a sample of up to 5 parents of children who had been through the statutory assessment of need process and who were willing to participate in a phone interview about their experience of that process. (See schedule in Appendix 2). Parents were drawn from across the spectrum of need. Having received the names and contact details of participating parents, the National Disability Authority made contact and arranged phone interviews with them at a time and date that suited them. The National Disability Authority also supplied an easy-to-read guide to the project for participating parents. This guide explained:

• the background to the project

- the purpose and importance of the project
- how information would be used
- that their participation could not in any way affect their child's service provision

The National Disability Authority also requested from assessment officers that a sample of anonymised assessment reports and any locally developed guidance, framework, templates, related to the statutory assessment of need process were made available.

All interviewees received assurances that neither they, nor their organisation nor their Local Health Office would be named in the final report.

### 2.3 Scope

This report looks at the operation of the statutory **assessment of need** under the Disability Act. Therefore, some of the mechanism established by Part 2 of the Disability Act 2005 fell outside the scope of this project.

This report did not consider the role of Liaison Officers. The Liaison Officer role is prescribed under the Disability Act 2005 but this report looked at the statutory **assessment** process under the Act whereas the Liaison Officer role relates to providing for **service delivery**. For this reason questions relating to service statements were not addressed.

Similarly, the operation of the complaints and redress mechanisms established under Part 2 of the Disability Act 2005 were not considered.

Also, this report is not, and does not purport to be, a review of clinical practice.

### 2.4 Sample selection

There was no published research on the operation of the statutory assessment of need process in multiple locations. It could not be assumed for the purposes of this study that the statutory assessment of need process operated in a highly uniform way throughout the country. This supposition was based on the variation captured in the Health Service Executive quarterly reports on the statutory assessment of need and on earlier discussions among assessment of need personnel which the National Disability Authority had observed.

The National Disability Authority identified a sample of eight Local Health Office areas which:

• have broadly representative estimates of children with disabilities<sup>27</sup>

<sup>&</sup>lt;sup>27</sup> These estimates were supplied by the Health Service Executive and are based on Census 2006 figures and assume a 4% disability prevalence rate

- have a broadly representative throughput of children through the statutory assessment of need process<sup>28</sup>
- had fewer overdue statutory assessments of needs than the national average<sup>29</sup>
- have equal representation across Health Service Executive regions
- have a spread across both rural and urban areas

As table 4 below shows the sample included a number of sites that had, at least as much, statutory assessment of need activity as the national average, but had a less than the national average of overdue assessment. (See Appendix 3).

	National Disability Authority's Sample	National Average
Estimated number of children with a disability 0 – 4	452	425
Milestone activity (throughput) - Quarter I, 2011	46	42.5
Overdue for completion - Quarter I, 2011	14.5	28.5

 Table 4 - Local Health Office Area Sample

Source: Central Statistics Office, 2007, Census 2006 and figures provided by the Health Service Executive (National Disability Unit) for the first 3 months of 2011

### 2.5 Interviews with professionals

40 interviews with assessment officers and assessors were conducted in the sample sites between the 8<sup>th</sup> and the 27<sup>th</sup> of June 2011. The interviews were structured. Each interview lasted about 90 minutes. The interview questionnaires for assessment officers, team / service managers and assessors can be found in Appendix 2.

The interviews were conducted with:

- 8 Assessment officers
- I Case manager (formerly an assessment officer)
- 7 Service managers / team leaders<sup>30</sup>

<sup>&</sup>lt;sup>28</sup> Based on figures supplied by the Health Service Executive's Disability Information Unit, which were based on 2011 activity to date as of April 2011.

<sup>&</sup>lt;sup>29</sup> Based on figures supplied by the Health Service Executive's Disability Information Unit, which were based on 2011 activity to date as of April 2011

<sup>&</sup>lt;sup>30</sup> The breakdown of the service managers / team leaders was 3 Psychologists, 2 Speech and Language Therapists, I Occupational Therapist, I Physiotherapist , I Early Intervention Team leader

• 24 Assessors

The 24 assessors included:

- 10 Occupational Therapists
- 5 Speech and Language Therapists
- 2 Physiotherapists
- 6 Psychologists
- I Psychiatrist

The purpose of the interviews with professionals, involved in the statutory assessment of need process, was to ascertain:

- How the statutory assessment of need process operated locally?
- Why had this local model, of operating the statutory assessment of need process, come about?
- How the statutory assessment of need process, as developed locally, related to assessment and intervention conducted outside the statutory framework?
- What are factors which contributed to successful working of the statutory assessment of need system?
- What the challenges are to the successful operation of the statutory assessment of need process?
- Are there specific issues in Part 2 of the Disability Act 2005 that may contribute to these challenges?
- What the understandings are of the legal underpinnings of the statutory assessment of need process, and what was the basis of such understandings?

### 2.6 Review of sample of assessment of need reports

The National Disability Authority received a sample of 40 anonymised reports on children who had been through the statutory assessment of need process in the selected Local Health Office areas.

The National Disability Authority in reviewing these reports wanted to establish what learning there may be in terms of:

- Consistency in use of the HSE template for reporting
- Consistency of approach in completing reports
- The manner in which reports were written easy to understand, concise, consistent
- Consistency in what was included in such reports in information such as:
  - Reason for referral
  - When the child was seen and by whom
  - Assessment tools and/or processes used

- Outcome of assessments
- Strengths and needs of the child
- Summary and recommendations
- Appropriate review period

It should be noted that the National Disability Authority only reviewed the summary reports and not any detailed reports that may have accompanied such reports.

### 2.7 Interviews with parents

The National Disability Authority interviewed up to 5 parents of children from each of the 8 Local Health Office areas who had been through the statutory assessment of need process. In total 33 parents were interviewed. The names of parents were supplied by the relevant assessment officer.

The interviews with parents were semi-structured and lasted between 30 - 60 minutes. The themes covered in the interviews were:

- Referral pathway to the statutory assessment of need process
- Decision to request the statutory assessment of need
- Expectation of the statutory assessment of need
- Service prior to commencing the statutory assessment of need
- Experience of the statutory assessment of need process
- Outcomes for child and family from the statutory assessment of need process
- The statutory assessment of need reports (in terms of how useful and understandable these are)

# 3. The importance of an integrated approach in the statutory assessment of need process

### 3.1 Integrated structures

The Local Health Office areas, that informed this project, had a variety of configurations as to how children were assessed and services were delivered. Some were solely Health Service Executive, others a mix of statutory and non- statutory agencies and others worked in an interagency partnership. All struggled with similar issues like:

- Delivering a statutory assessment of need within the statutory timeframes
- The appropriateness of some of the language of the Disability Act 2005 in the context of delivering supports to children, particularly young children,
- Trying to ensure that they operated in the best interests of the child
- Attempting to ensure equity between a statutory assessment of need and other assessments and managing waiting lists and priorities
- Dealing with impacts on service provision such as reduced resources

What was striking was that Local Health Office areas seem to be better able to cope with the requirements of operating Part 2 of the Disability Act 2005, where there were integrated structures with:

- good cooperation among clinicians
- co-working
- coordinated early intervention teams

### 3.2 Importance of an integrated structure

The most illustrative way to convey how an integrated structure contributes to reducing the impact of some of the key challenges to operating a statutory assessment of need process is by comparing case studies. These case studies (like the rest of the findings of this paper) are based solely on the interviews conducted with the personnel involved in the statutory assessment of need process.

The two case studies represent the opposite ends on a spectrum of integration in early intervention / children's services. Most of the other six Local Health Office areas had some degree of integration or coordination. The variation across the 8 Local Health Office areas is discussed in Chapter 4 and positive elements of the arrangements delivering the statutory assessment of need process across all 8 Local Health Office areas are discussed in Chapter 5.

The findings set out in sections 3.2.3 and 3.2.4 are based on the evidence of all 8 Local Health Offices areas but for the sake of illustration and clarity on the diversity of approaches taken, two very different cases are described below.

### 3.2.1 Case study I - Local Health Office area

This Local Health Office had a throughput of about 100 children in the first half of 2011 and had about 60 assessments overdue in the same time period.

In this Local Health Office Area service delivery for children with disabilities, prior to the introduction of the statutory assessment of need, was primarily the responsibility of a number of disability-specific agencies. Since the introduction of the statutory assessment of need process, one Health Service Executive Early Intervention Team has been established, although putting a full complement of clinicians in place took time. However, a process to integrate the Early Intervention Team with paediatric resources within primary care or with agencies delivering early intervention / children's services in the Local Health Office has not yet commenced.

Prior to the introduction of the statutory assessment of need, children with disabilities were typically referred directly to the agencies by the Area Medical Officer and clinicians working in primary care. Additional investment in early intervention and children's disability services was directed to existing agencies. As a result, no additional resources were put into paediatric assessment and intervention within primary care.

Agencies took responsibility for all children with disabilities related to their area of service provision. Agencies could gate-keep and manage waiting lists by using clinical judgement to prioritise children.

When the statutory assessment of need process was introduced in this Local Health Office Area it had to contend with the legacy of the existing service delivery configuration:

- agencies were reluctant to move away from the systems that had worked for them in terms of concentrating their resources on children who most need their services
- primary care / community services were ill-equipped to perform statutory assessments of need children or perform subsequent intervention

No structure to coordinate early intervention services and/or children's services existed nor has developed over time to coordinate, among other things, the statutory assessment of need process. Currently, some tentative efforts at developing a more collaborative relationship are underway but at present the statutory assessment of need personnel, early intervention team personnel, paediatric community resources and disability agency managers operate largely independently of one another.

Children who clearly meet the eligibility requirements of the agencies continue to be referred by the Area Medical Officer and primary care professionals to the appropriate agency.

However, children with needs for services other than those delivered by the existing agencies, and children who would be low priority for the existing agencies, are referred to the statutory assessment of need process. In time children who primarily

need school-based supports are also referred to the statutory assessment of need process.

In the context of current financial constraints, agencies are arguing that they are funded to provide supports for children with certain diagnoses and do not have a responsibility to perform a statutory assessment of need on children other than for those children who have a diagnosis and for whom they are responsible. Children accessing these services typically have a diagnosis prior to entering the service.

Increasingly, parents whose children don't fit the eligibility requirements of the existing services, and who are frustrated by lack of access to services, are referred by various professionals to the statutory assessment of need process.

As the disability agencies are still operating disability specific services for those children with certain diagnoses, those conducting statutory assessment of need know that children **will need a diagnosis to access services**.

In such circumstances, some assessors feel compelled to perform full diagnostic assessments up front. The service configuration, within certain agencies in their Local Health Office area, means that a child with an initial assessment highlighting their needs at a point in time would not be able to access intervention. As one assessor noted:

### Senior Occupational Therapist – Early Intervention Team

"A quick play-based assessment would be fine if you were keeping the child in your service but we're not. If the children we are assessing are going to get any intervention it is going to be in one of the agencies. The agencies will not accept a play based assessment. They have long waiting lists and their criteria are very tight. It would be completely unethical to perform an assessment that would be of no use to the child or family".

In these circumstances the statutory assessment of need process becomes a de facto pre-services diagnostic assessment. These full diagnostic assessments are timeintensive and result in less resources being devoted to intervention and less time to assess children who are not referred via the statutory assessment of need process. A knock-on effect of this appears to be that more parents apply for statutory assessment of need.

### 3.2.2 Case Study 2 - Local Health Office Area

This Local Health Office had a throughput of about 100 children in the first half of 2011 and had about 6 assessments overdue in the same time period.

In this Local Health Office Area, a review of services for children was carried out prior to the commencement of the statutory assessment of need process. The review found that the service provision was a mixture of a number of disability-specific services and the resulting service provision was fragmented and inefficient. The outcome of the review was a decision to use existing and new development funding to establish an integrated structure. This structure had generic teams responsible for all children with disabilities within defined catchment areas. The development and introduction of this structure took time, met with some opposition and had its challenges.

Prior to the introduction of the statutory assessment of need there was a clear pathway in place for children entering services. This pathway was underpinned by common understandings of shared eligibility criteria and approaches to assessments.

This has meant that the child accesses the same level of service irrespective of where a child is referred to. Critically, it has also meant that children receive the same assessment, within the same timeframes whether or not they apply for a statutory assessment of need. This means that there is no incentive to apply for a statutory assessment of need, such as "jumping the queue or getting access to a service quicker". In practice this is seen as significantly reducing the demand for a statutory assessment of need.

Some of the critical elements of the integrated structure in this Local Health Office Area include:

- GPs and Public Health Nurses often first point of contact with the child and families. What appears to be crucial here is that work seems to have been done with both the GPs and Public Health Nurses and as one psychologist put it "they are on the ball" when it comes to referring children on
- Team assessment (on average I 2 hours) which looks at medical history, developmental milestones and parental concerns. Teams, though critical of the language of the Disability Act, have come to terms with the idea of conducting brief initial assessments to identify needs for the next twelve months, whether the assessment is a statutory assessment of need or not.
- Inter-disciplinary assessment which looked at
  - Play and learning (Occupational Therapist/Physiotherapist)
  - Communications (Speech and Language Therapist)
  - Gross motor(Physiotherapist)
  - Fine motor, visual motor, sensory processing (Occupational Therapist)
  - Teams nominate an appropriate number of team members (typically two members) to conduct an initial assessment, whether the assessment is a statutory assessment of need or not
- Reports are completed and children with more complex needs are referred on as required for more in depth assessments and/or interventions
- The existence of a number of generic teams allows the assessment officer to manage the statutory assessment of need workload so as to avoid any one team getting too many referrals in too short a period of time

• Common agreement across the Local Health Office area on what the requirements of the statutory assessment of need are has allowed the assessment officer take on the role of monitoring and providing some general feedback to teams on assessment reports provided by them as part of the statutory assessment of need process

# **3.2.3** Assessors perform the type of assessments required for children to get the supports that they need

The key point that the case studies illustrate is that if the service delivery system is fragmented into disability specific organisations with tight eligibility criteria, then it would appear that assessors, conducting statutory assessment of need, are highly unlikely to come to the view that brief initial assessments are in a child's best interests. They appear to hold this view as such assessments will not in fact meet the requirements of the service delivery system.

Assessors, in the interviews conducted for this report, indicated that in conducting statutory assessments of need, they are very mindful of the resource allocation **rules** of the service system – the education system primarily but also the health funded services in some instances - which children need to enter to get intervention/support.

This point is even more clearly evidenced in relation to the attitudes and practice of assessors conducting a statutory assessment of need of school-aged children. The interviewees made it clear that they felt the resource allocation rules within the education sector place a significant pressure on them to perform full diagnostic assessments of school aged children. Many assessors cited a sense of professional and ethical duty to conduct assessment that would unlock resources with the education sector (see also Section 8.4).

### 3.2.4 Incentives for pre-service statutory assessment of need

A service configuration, which is dominated by organisations which require a diagnosis in advance of providing a service, appears unsurprisingly to generate a demand for assessments and, in particular, for diagnostic assessments. The statutory assessment of need process then becomes very attractive to parents and referring professionals. It can deliver an assessment (and in practice often a diagnosis) within a short timeframe for a child not currently in a service.

Conversely, there will be very little incentive to apply for a statutory assessment of need where there are clear pathways to services. Where such pathways exist, there are few obstacles to accessing an assessment (whether it is part of the statutory assessment of need process or not) and service eligibility criteria are typically based on presenting need and not on a specific diagnosis.

# **3.2.5 Statutory assessment of need process and configuration of service delivery**

Based on the evidence of interviews the following points can be made on the relationship between integrated services and **the operation of the statutory assessment of need process**:

It is difficult to divorce resource allocation and the service access **rules** of the service delivery system and an assessment of need process

- The introduction of the statutory assessment of need process in 2007 was not accompanied with any national programme to align resource allocation/service access rules of the service delivery system, though some alignment did take place in some areas
- Assessors conducting statutory assessment of need appear to be mindful of the resource allocation and the service access **rules** of the service system which children need to enter to get intervention
- A service configuration which is dominated by organisations which require a diagnosis in advance of providing a service appears to generate a demand for diagnostic assessments

## 4. Variability in the operation of assessment of need

There are marked differences in how the statutory assessment of need system operates in between different Local Health Office areas and to a lesser extent within Local Health Office areas.

# 4.1 Difference in local structures operating the statutory assessment of need process

As described in Chapter 3, there are very different early intervention and children's disability service configurations across the 8 Local Health Office areas. The various service configurations can be described in three ways:

- 1. **Fragmented** service delivery dominated by disability-specific organisations which use a diagnosis as the basis of service eligibility. It has no overarching coordinating structure incorporating all stakeholders, including the assessment officer
- 2. **Coordinated** mixed service delivery configuration featuring both generic Health Service Executive generic resources and disability-specific organisations. Some overarching structure is in place to refer all requests for assessment (statutory and non-statutory) and intervention to the appropriate service. The assessment officer is a stakeholder in this structure
- 3. **Integrated** service delivery is dominated by generic teams, who cover children with all disabilities (referred by a statutory and non-statutory route) from given area and who operate non-diagnosis based eligibility criteria. The assessment officer is a stakeholder in this structure

The local structures that are in place will influence the type of assessment the child will receive irrespective of whether the child was referred through a statutory or non statutory route. In particular it will influence whether a child will typically receive a relatively quick assessment aimed at identifying presenting service needs (including the need for further assessments) or a more in-depth diagnostic assessment. Local structures appear to have this influence because assessors are very aware of operating service eligibility (such as gate-keeping by linking service eligibility to a diagnosis) rules and of the services from which parents are seeking support.

# 4.2 Differences in relationship between statutory assessment of need mechanisms and Child and Adolescent Mental Health teams

Assessment officers in some areas indicated that it was not possible to get Child and Adolescent Mental Health teams to agree to assess children under the statutory assessment of need process.

As a result, children with a mental health issue or children with a mental health issue and another disability will receive different assessments depending on which Local Health Office areas they live in.

### 4.3 Differences in how teams operate

Some multi-disciplinary teams provide a uni-disciplinary assessment by individual therapists to all children regardless of whether they have needs in one or more areas. Other teams provide a multi-disciplinary team based assessment to all children with needs in two or more areas. This they contend is in line with best practice.

Some multi-disciplinary teams have decided that **all** professionals – including in one case a paediatrician – should participate in **all** team-based assessments. Other teams nominate some team members to conduct the assessment based on presenting information.

Some teams have insisted that at least one standardised tool be used during multidisciplinary assessments while others have decided that a play based assessment will suffice.

# 4.4 Differences in person hours required to conduct a statutory assessment of need

As part of this project, assessors were asked how long they typically take to conduct a statutory assessment of need. It emerged that there is very significant variation in the person hours assessors felt were required to conduct a statutory assessment of need. For example, one assessor indicated that the average person hour commitment to a statutory assessment of need was 10 times greater than a colleague in the same discipline, working with the same age cohort but working in a different location. This issue is discussed in more detail in section 7.3.

### 4.5 Differences in assessments that children will receive

There was considerable variation between Local Health Office areas as to whether a statutory assessment of need should:

- include all assessments that a child needed or
- recommend that more specialised assessment or assessments in other areas of need could form part of the recommendations arising out of an assessment of need process (see also 8.2)

### 4.6 Variation in assessment processes: concluding remarks

Children with similar needs may receive very different assessments depending on which Local Health Office area they happen to live in. The principal driver of these differences appears to be the service configuration in operation in a given Local Health Office area.

Variation is not necessarily a bad thing. Variation allows different solutions to be tried and tested. Chapter 5 explores some mechanisms that the 8 Local Health Office areas have put in place to overcome some of the challenges posed by the statutory assessment of need process. However, for variation to contribute to improvement and learning it has to be captured and shared. It is critically important that variation does not result in children receiving a poorer service or having poorer outcomes.

For both of the reasons outlined above it may make sense for performance data to be matched to categories of Local Health Office structures (that is, whether services are integrated or not) at least for learning purposes.

# 5. Factors which may contribute to better local statutory assessment of need processes

This section deals with a number of challenges that professionals identified in carrying out a statutory assessment of need. It also highlights some of the solutions and/or practices they implemented in an effort to address some of the challenges.

The main challenges identified by professionals include:

## 5.1 Timeframe for completion of forms

Issues for professionals in this regard were:

- statutory timeframes
- comprehensiveness of the report
- fitting it in to their existing workload

Some of the local solutions that were adopted included:

- rotating responsibility for ensuring completion of reports on time among the team
- confidential sharing of completed reports among their own specific professional peers. This facilitated learning among each other regarding descriptions of need and outcomes. This in turn lead to more consistency in language used and a basic frame of reference
- assessment officers periodically reminding teams of the purpose of the statutory assessment of need process and of how comprehensive or otherwise the teams' reports need to be

## 5.2 Assessing children with complex needs

A range of issues were highlighted regarding assessing children with complex needs, in particular, children with autism spectrum disorder, within the statutory assessment of need process. Some of these issues included:

- the need for comprehensive assessments in relation to Autism Spectrum Disorder
- the varying lengths of time taken by different professionals in carrying out such assessments
- waiting lists for such assessments

Some of the local solutions that were adopted include:

One Local Health Office area had established an **autism consultation forum**. This forum met once a month and dealt with 2 cases at each meeting. Each case discussion lasted one and a half hours. It reviewed all the background information available on the child; the assessment(s) to date and reviewed video footage taken of the child during assessments.

The Forum is chaired by a psychiatrist with an Autism background and its members include a Senior Speech and Language Therapist, Occupational Therapist; Psychologist; Psychiatrist (child and adolescent mental health service). While there is a small waiting list in bringing cases to the Forum, the local practitioners find it an invaluable mechanism in the assessment process.

## 5.3 Assessment and intervention

One of the issues cited by a number of assessors was that the workload involved in carrying out the statutory assessment of need meant that they were unable to provide/continue to provide any intervention services. Essentially, it appears that in having to address the volume of people requesting a statutory assessment of need, that this had to be prioritised and a significant amount of time was dedicated to this task.

In a number of Local Health Office areas this dichotomy between an assessment versus intervention did not seem to exist. In such situations practitioners indicated that assessment always involved some degree of intervention and that it was part of a process along a continuum.

In one area, they had piloted an early intervention and observation process. This was for all children, irrespective of whether there was a requirement for a statutory assessment of need. A key worker was assigned to the child and family. An initial visit was undertaken in the home and initial dialogue on the child's needs and family circumstances took place.

There was a 6 week programme provided in group session with usually 3-4 practitioners (for example, psychologist, speech and language therapist, physiotherapist). The sessions last one and half hours with up to 4 children similar in age and with similar presenting issues. These sessions were focussed on interaction and observation and a clinician could withdraw a child if needed to do so for a one to one session during this time. Such sessions formed part of the statutory assessment of need process and also enabled intervention to be provided.

## 5.4 Local structures

As discussed in Chapter 3 local structures play an important role in how the statutory assessment of need is delivered. What was clear from the Local Health Office areas is that a range of local solutions were applied in addressing issues such as:

- how applications for statutory assessment of need were completed
- how the balance could be struck between fulfilling the statutory obligations for assessment of need within specified timeframes and, at the same time, maintaining services and continuing assessments for children who did not come the statutory route
- reducing backlogs for assessments for children who did not come through the statutory assessment of need process

The various solutions at local level are underpinned by characteristics such as:

- good co-working
- people working as part of a team
- positive relationships between assessment officers and the early intervention teams and heads of disciplines in community based services
- constructive formalised engagement with other professionals such as social workers, for example, meeting once a month

## 5.5 Two-tier system

Section 7.1 discusses in more detail how the statutory assessment of need process has contributed to the development of a two-tier system of assessment in Local Health Office areas with some children being on a non-statutory waiting list for an assessment and some children being assessed as part of the statutory assessment of need process. In some cases the timeframes for the non-statutory waiting list for an assessment are significantly longer than the timeframes associated with the statutory assessment of need.

With regards to addressing this unintended consequence of Part 2 of the Disability Act, which results in a "two tier" assessment system, one practical solution identified was to set aside dedicated time for assessments by a multi disciplinary team.

The local structure underpinning this solution comprised a number of elements:

- Public health nurse doing an **Ages and Stages** type questionnaire with the family in the home. This assisted in making a determination of what the child may need. It also supported parents in completing application forms for a statutory assessment of need
- Setting aside a number of days a month for assessments and having a balanced ratio of statutory and non-statutory assessments. A multi disciplinary team carried out the assessments
- Once a month holding a multi-disciplinary screening clinic open to any child and family to attend. This enabled a basic screening and appropriate referral to community-based services, and further assessment and intervention where required. This helped reduce the notion that "the only way to access such services and/or assessment was through the statutory route"

## 5.6 Alignment between the statutory assessment of need and other assessment processes

Some Local Health Office areas developed a number of strategies to align the statutory assessment of need with other assessment processes. These included:

#### Referral forum/team referral/case panel meeting

These mechanisms are multi-disciplinary in nature and determine the appropriate assessment and/or service a child may need. They typically consist of heads of discipline. They review all referrals for assessment (statutory and non-statutory) and intervention that may be required. They collectively determine the most appropriate path for that assessment/intervention, for example, single assessment or multidisciplinary assessment and/or intervention service a child may need.

Such mechanisms to facilitate coordination have developed in some Local Health Office areas where service provision is still quite fragmented and have addressed some of the issues associated with areas where service fragmentation has led to unsustainable pressures on the statutory assessment of need process.

#### • Single set of documentation / templates for all assessments

One early intervention team interviewed for this study had experienced several instances of children who had been assessed by their service, subsequently requesting statutory assessment of need (often because they requested a statutory assessment of need while on the waiting list for a non-statutory assessment). In response the team developed report templates which facilitate non-statutory assessment reports being formatted in such a way that they can be submitted as statutory assessment reports if required.

### 5.7 Stakeholder views of integrated coordinated teams

The vast majority of assessors, assessment officers and service management team leads clearly were supportive when asked questions like "Has/would the integration of early interventions services/children's services made/make the operation of Part 2 of the Disability Act 2005 easier or not?" In responding to this question people referred to various types of teams, such as:

- Multi-disciplinary
- Early Intervention Teams
- Health Service Executive and voluntary bodies integrated
- Coordinated teamwork

#### Assessment officers

"Absolutely ....when you have coordination the clinicians are in place and there is access for children to a service..."

"Yes.....it provides a clear defined pathway for children and their parents..."

"Absolutely ...you have teams on the ground....and well developed early intervention services are critical....initially a child will get a screening but then has access to an immediate service and can progress from there..."

#### Service managers/team leads

"... multi-disciplinary teams are the way to go....you need a cross section from different disciplines – it has credibility....."

"...it provides the opportunity for levelling off of case loads. You can't be an expert in everything...there are particular skills with working with children with Autism and then having to work tomorrow with a child with cerebral palsy. So it is important to have the right balance in the team approach depending on the child's profile..."

#### Assessors

"...being separate is counter-productive ....... I have found working as part of a multi-disciplinary team to be much better both in terms of the child and being able to support the family..."

"....I have found it really useful in "grey areas" where children could fall between the cracks, where they have complex needs and these can be explored together in a multi disciplinary setting ..."

### Parent

One parent interviewed had one child who had to go through a range of uncoordinated assessments and another child who had access to a multi- disciplinary team. The parent remarked:

"I was overwhelmed by the number of individual appointments I had to go to and found it physically and mentally exhausting and lost as to what was happening and what was going to be the outcome for my child. A few years later when I had to bring my other child for assessment I could not believe the difference when I met with 3 professionals at the same time and the support that was there in that I could contact any one of them and they knew exactly what was going on for my child....it was fantastic"

# 6. Nature of disabilities of children coming through assessment of need under Part 2 of Disability Act 2005

This section looks at clinicians' views of what children go through assessment of need and which children the assessment of need process is most suitable for.

## 6.1 Nature of the disabilities of children coming through assessment of need

Calculations by the Health Service Executive show that approximately 50% of eligible children apply for a statutory assessment of need under the Disability Act<sup>31</sup>. None of the literature available suggested any explanation why 50% of those children likely to be eligible do not get referred to receive a statutory assessment of need under the Disability Act or whether there was any pattern to those who get referred. However, what was clear from the Health Service Executive figures is that in some Local Health Office areas far more children apply for statutory assessments of need than in others.

The interviews conducted with assessors and assessment officers asked them whether in their view there is a pattern to the children who are being referred to them for assessment under the statutory assessment of need process.

#### Senior Clinical Psychologist, working on a school-aged team:

"There have been some Specific Language Impairment queries, one child with a mild intellectual disability but most of the AON referrals to date have been query autism. This would include a lot of very poor query autism referrals"<sup>32</sup>.

#### Assessment officer:

"There are very clear patterns to who is likely to be referred to the AON route. Autism would be the most likely, then children with Specific Language Impairment, then children trying to access Children and Adolescent Mental Health Teams"

## Senior Clinical Psychologist, working on a school-aged team and seeing children under 5 as part of a private practice:

"A lot of the children referred to us don't have a disability. They may have some special education need and they are using the AON as a way of getting a psychology assessment. Children with an established

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http://www.hse.ie/eng/services/Publications/services/Disability/rptimpdisact2005.pdf
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<sup>&</sup>lt;sup>31</sup> Health Service Executive, 2010, Report to the Minister for the Equality, Disability, Mental Health At the Department of Health and Children as provided for under Section 13 of the Disability Act 2005 - In Respect of the Data Collected in 2008 and 2009

<sup>&</sup>lt;sup>32</sup> In these direct quotes LHO refers to local Health Office area; AON refers to the statutory assessment of need under Part 2 of the Disability Act; Non-AON refers to all other type of assessments; NEPS refers to National Educational Psychological Service

disability in this area are in our services. It is extremely rare that a child who is in our service would request an AON. The vast majority of school-aged AON requests are parents or schools trying to get a psychology assessment for resources for the child in school".

"The AON as it is set up here has no filter system. A child, whose parents feel they have a disability, is given a very expensive, very time consuming assessment. We had AON requests for 14 children from one infants' class. It transpired that they were referred by one teacher because they had poor handwriting. They were all given an AON. There needs to be some filtering process, some determining criteria before an AON is triggered. Young children being referred to AON should all have an Ages and Stages screening. If that is not flagging needs on two domains should not be referred to AON".

#### Senior Occupational Therapist – Early Intervention Team

"The children that are referred to us are those with borderline conditions or general development delay without any diagnosis of an underlying condition and those with query ASD. Children with lifelong or established conditions tend not to come through AON, largely, I imagine, because they are already in our service"

### Senior Speech and Language Therapist – part-time Early Intervention Team and part-time Community Team (0 – 12 years)

"There is no pattern to the referrals of children we see anymore. We have made the decision to put all children with underlying disabilities or needs in two or more areas through the AON process, so children right across the spectrum now receive an AON as a matter of course. It was felt to be too unfair to have some children skipping waiting lists, so all children meeting the criteria for early intervention will get an AON while they are with our service"

#### Senior clinical psychologist – Early Intervention Team

"We have a good early intervention forum here, so children who meet the criteria for other services are referred to those services. The children who are referred to us via AON are children with needs in two or more areas but who don't fit the entrance criteria for other services in the area. Children with a diagnosis of a lifelong disability won't come to us via an AON referral for an assessment. Many of those referred via AON shouldn't be but there is no filter system".

#### **Assessment officer**

"In recognition of the fact that our school-aged services are nowhere near as well resourced or as well coordinated as our early intervention services, all parents of children exiting the early intervention services are now being encouraged to apply for AON. This is an attempt to provide a structure for them when they exit our early intervention services".

### Principal Speech and Language Therapist - Community based

"Child with more complex needs are referred to AON. Often, however, they are not that much more complicated than those we see in the community. What often happens is that when we think that we need an Occupational Therapist or a Psychologist to assess a child the only avenue open to us to access AON assessment".

### Senior Speech and Language Therapist – Early Intervention Team

"We make all parents of children with two or more needs aware of the AON process. The vast majority don't apply. Every now and then a group of parents of children who are already in our service will all apply for an assessment of need. It is hard to understand why a parent of a child who is a fairly well resourced service would apply for an AON".

Table 3 in chapter 1 of this report provides a breakdown of the category of disability of children who have been assessed under the Disability Act 2005 for the first nine months of 2011. The categories of "physical", "sensory" and "intellectual" combined only account for 6.5% of those coming through the assessment of need process. As mentioned previously, autism, primary speech and language and "no category" represent nearly 60% of the disability categories of the children assessed under the statutory assessment of need.

It is difficult to interpret the above figures in isolation. The Intellectual Disability Database and the Physical and Sensory Disability Database provide an indication of the use of services of children in the relevant age cohort<sup>33</sup>. Details of the numbers of children under 9 accessing disability services in 2011 as per the disability databases are shown in table 6 (which is located in appendix 6). These figures provide limited scope for comparison<sup>34</sup> against the statutory assessment of need data but they do reinforce some of the views expressed by professionals cited above. In particular, they provide some weight to the view expressed by many interviewees that the vast majority of the 3,637 children with intellectual disabilities in the relevant age cohort access services without engagement with the statutory assessment of need process.

<sup>&</sup>lt;sup>33</sup> The eligible cohort of children for a statutory assessment of need in effect extends to children under 5 at on the 1<sup>st</sup> of June 2007. This, for example, includes all children under who were under 9 on the 1<sup>st</sup> of June 2011. Please see section 1.1.3 for an explanation of the age cohort that is eligible to apply for a statutory assessment of need.

<sup>&</sup>lt;sup>34</sup> The categories of disability on the Intellectual Disability Database and the Physical and Sensory Disability Database do not fully match the categories in the Health Services Executive statutory assessment of need report. In particular the two databases don't cover mental health. Also, it is not required that information on those using disability services for people with physical and sensory disabilities register with the Physical and Sensory Disability Database.

## 6.2 Influence of local service configuration and local understandings of assessment of need on those children going through this process

A number of patterns emerged regarding those children who are being referred for a statutory assessment of need. In the majority of the areas covered by this report, there appeared to be an underlying assumption that the statutory assessment of need process was generally not for those who were in services and generally not for those who already had diagnosis of a disability. The statutory assessment of need process in many areas appears to have become a route to assessment for those children who do not fit into existing service categories.

In one of the areas covered by this report a recent change of policy meant that all children with needs in two or more areas were being put through the statutory assessment of need process. This development was in its infancy and its sustainability was still under consideration at the time the interviews took place. The origin of this approach was a response to the perceived inequity of a system where some children went through a statutory assessment of need process and some did not.

There was one example of where statutory assessment of need process was being used, among other uses, for children who were making a transition from early intervention services to school aged services. This was to ensure that children didn't get "lost" in the system when they moved away from early intervention services. This was also a relatively recent development.

The interviews conducted for this report suggest that service configuration in an area does shape which children are likely to be referred to the statutory assessment of need process. The understandings by professionals involved in the statutory assessment of need - some professionals outside the process, particularly teachers – also shape which children are likely to be referred to the statutory assessment of need process. The implications of this issue are taken up in section 8.1.2.

# 7. Impacts on the assessment of need process – professionals' views

This section examines a number of the issues raised by professionals operating the statutory assessment of need process, including obstacles which restrict the efficient functioning of this process.

## 7.1 Creating a multi-tier system of access to services

The most common criticism made by professionals of the statutory assessment of need process was that it resulted in a multi-tier system of accessing assessments and services. In many areas the waiting times for assessments are longer than those associated with the statutory assessment of need process. Waiting lists are often prioritised based on need. The statutory assessment of need process provides a timeframe in which assessments will be completed. It may, in some cases, provide an avenue for some people who would not be considered a priority to reduce their waiting time for an assessment.

The following quotes are typical of what the National Disability Authority heard from interviewees<sup>35</sup>.

## Senior Clinical Psychologist - Early Intervention Team

"We have a referral forum for early intervention services across the whole LHO. Children are referred to referral lists for services from the forum. Those referrals are ranked in terms of priority. Those prioritisations are reviewed as new information is made available. That system works and is fair. Then we have our Non-AON referral list. The statutory timelines determine the prioritisations for that list, not presenting need. We frequently delay assessing or intervening with children with greater need because we are conducting AONs. The children who come through AON often have lesser needs than those we have had to push further down the non-Aon lists. That is unfair and a poor use of time and resources".

## Senior Occupational Therapist – Early Intervention Team

"We have two waiting lists for those seeking an initial assessment; our early intervention waiting list and our AON waiting. We have been under huge pressure to clear our AON waiting list. To my mind the main difference between children on the AON list and the early intervention list is that the parents of those children who have

<sup>&</sup>lt;sup>35</sup> In these direct quotes LHO refers to local Health Office area; AON refers to the statutory assessment of need under Part 2 of the Disability Act; Non-AON refers to all other type of assessments; NEPS refers to National Educational Psychological Service

demanded an AON are more demanding, better educated and more affluent. It certainly has nothing to do with level of need."

The way services for children with disabilities have evolved in Ireland has meant that service provision can be uneven and that, "some children and their families have little or no access to services" (see also Section 1.3.3). This uneven pattern of provision can be between age cohorts (early intervention or school-aged) or between disability categories.

Therefore, in most of the Local Health Office areas reviewed, there were three categories of children with disabilities or delayed development:

- I. Children receiving services
- 2. Children on non-statutory assessment waiting lists
- 3. Children receiving a statutory assessment of need

There are two different views about the effects of the statutory assessment of need in this context. These views are that:

- the statutory assessment of need provides a route to an assessment for children who would not fit the criteria for existing service provision
- the statutory assessment of need process is undermining prioritisation arrangements and facilitating "wait list hopping". This was seen as having added further tiers in the process of accessing services in an already uneven system

## 7.2 Accessing other entitlements

Most assessors interviewed highlighted that the statutory assessment of need process was used as a means of accessing services other than the health and personal social services delivered by or on behalf of the Health Service Executive. Some assessors mentioned that print and online guidance for the Domiciliary Care Allowance and for exemptions to the Early Childhood Care and Education scheme<sup>36</sup> mentioned the statutory assessment of need process. Some assessors had requests for a statutory assessment of need which ultimately transpired to be related to applications for these schemes.

Almost all the professionals interviewed highlighted that some of the referrals for the statutory assessment of need process were indirect referrals from teachers or schools.

#### Senior Occupational Therapist – Early Intervention Team

"We did have some referrals from which were coming from schools. Actually it was one school. Very few of the referrals were relevant.

<sup>&</sup>lt;sup>36</sup> While application information for the Domiciliary Care Allowance and for exemptions to the Early Childhood Care and Education scheme mention the statutory assessment of need process they do not indicate that a statutory assessment of need is required. It appears, however, that some parents or professionals may have misinterpreted this.

Parents were coming saying their child was fine as far they were concerned but the school wanted them to have an AON to prove that they didn't have a disability. We eventually flagged it with the assessment officer who spoke to the principal and the practice stopped."

## Senior Clinical Psychologist, working on a school-aged team and seeing children under 5 as part of a private practice

"Education sector is heavily influencing who is referring to AON. It is only some schools though are switched on to it. These schools are using the HSE to supplement their NEPS allocation. When you see these referrals coming in you can spot them straight away. Sometimes the schools have even written down what people should say. You feel like opening and closing the referral but you have to meet the child and family as you have a duty of care and would be worried if anything clinical did show up later on. It is a really poor use of limited time and resources".

#### Assessment officer

"We have had a very significant increase in education referrals. In fact the majority of our applications are school-going children, for whom schools are the ultimate referring agent. Specific schools catch on to it, it is not all schools. They use it to augment the allocation that they get from NEPS."

#### Assessment officer

"Referrals from the education sector are a huge issue. Teachers think that AON will get them psychology determination that will get the child what they need in school. At the moment the principal psychologist is opening and closing some AON referrals on the basis of the written application and support documentation. If it's a NEPS case the AON application is closed and referred to NEPS".

It should be noted that some of the parents interviewed for this process spoke about how schools had supported them in the process of understanding that their child had a disability rather than a special education need. Similarly, the professionals interviewed were not claiming that all indirect referrals from schools were inappropriate.

The extent to which indirect referrals to the statutory assessment of need process from the education sector were perceived as being inappropriate differed between areas. There did not appear to be any particular pattern as to why it was more problematic in some areas than others. The options available to assessment officers and/or local disability service managers to tackle inappropriate referrals from schools appear to be quite limited at present.

## 7.3 Differences in assessment duration

There was the highest degree of consistency between assessors regarding the time needed to conduct a statutory assessment of need and other similar assessments for

service eligibility. The 24 assessors and seven service/team managers all said that there was no difference in the time required to conduct statutory assessment of need and other similar assessments for service eligibility. The assessments for a statutory assessment of need were likely to be condensed into a shorter period of time but involve the same amount of hours to conduct.

There was, however, significant variation between teams, individual assessors and Local Health Office areas in terms of the amount of person hours spent on a statutory assessment of need. For example, one senior Occupational Therapist estimates that each statutory assessment of need, including all report writing, had taken them 40 hours to complete<sup>37</sup>, while another Occupational Therapist in a different Local Health Office area estimated that, on average, each statutory assessment of need took about 4 hours. There was variation across all disciplines but it was greater in some.

Table 7 in appendix 7 provides more detail on the number of person hours that clinicians took to complete an assessment of need.

Some multi-disciplinary teams required all disciplines (including a paediatrician in one case) to be present for all assessments (statutory and non-statutory). Other multidisciplinary teams nominated two disciplines based on the two most presenting significant areas of need.

There appears to be significant differences between Local Health Office areas and individual professionals in the amount of time and resources being committed to assessing young children with disabilities. This variation does not appear to be driven by the requirements of the Disability Act 2005 alone.

It does not appear that clinicians are forced by the requirements of the Disability Act 2005 to conduct more comprehensive assessments. It is the case that a statutory assessment of need has to happen within a much shorter timeframe than other similar assessments, which assessors said, has the effect of causing other work to be pushed back. It may well be that the statutory assessment of need process has channelled more resources into assessment at the expense of intervention (as some interviewees argued) but this does not appear to be related to the statutory assessments.

## 7.4 Interpretations of "nature and extent"/determination of disability still cause difficulties

As mentioned in the introduction, one of the issues that clinicians and others have raised from when the statutory assessment of need process was commenced is that making a determination of a disability and / or describing the "nature and extent" of the disability, within the timeframes laid down by the Disability Act 2005 and the accompanying regulation, is difficult and in some cases inappropriate.

<sup>&</sup>lt;sup>37</sup> This relates just to the Occupational Therapist's hours not to hours of other professionals involved in the process.

The vast majority of assessors interviewed find that the language of Part 2 of the Disability Act 2005 is problematic in the context of assessing young children and particularly in the context of service provision models that are based on resources being linked to diagnoses. The quotes below are typical of the views expressed by many of the interviewees:

#### Speech and Language Therapist – Community based

"Stating what the nature and extent of the disability is difficult. For some kids it may be straight forward for others it is not. Some kids can make massive progress in six months ..... with lots of kids you honestly have no way of knowing whether or not whether the delay they have will be a feature in two or three years time ..... the term "disability" is just not appropriate for some young kids ..... labelling a child who has a delay and has needs as having a disability is not appropriate and many parents are justifiably unhappy and upset about it."

### Clinical Psychologist – Early Intervention Team

"I think that did create a lot of confusion initially. I would be very uncomfortable labelling a child as disabled. In time we have become more comfortable with report that the child has a delay, give the test results, but say that the nature and extent of the disability is not possible specify at the this time. That appropriate for young children but for kids in school or about to go to school. Schools have told parents that need a strong diagnosis."

#### Principal Speech and Language Therapist - Community based

"We understand that the idea of the Disability Act was to move away from focusing on a diagnosis and developing a system to unlock resources for a person with a disability based on their needs. However, the truth is that a child without a diagnosis gets nothing in our system. We can't get a child without a diagnosis into a service. They will certainly get nothing in the schools system without a diagnosis. This is a huge ethical dilemma for professionals."

Saying whether or not a child has a disability and what the nature and extent of that disability appears to remain a difficulty for most clinicians. Clinicians in some areas appear to have developed an approach to conducting a statutory assessment of need and filling in summary reports which gives them some comfort around this issue. These teams (and it was more frequently teams, based on the evidence of this report) have developed a language around just profiling needs as they presented, using "unspecified delay" as a term and "more than 12 month delay" as a descriptor for the nature and extent of the disability.

## **Occupational Therapist – Early Intervention Team**

"I think that used to cause lots of problems. Now where a child doesn't have a pre-existing diagnosis we just report the needs and in relation to "nature and extent of disability" we just say whether or not the delay is 12 months or more and whether that delay is impacting on functioning."

### Senior Occupational Therapist – Early Intervention Team

"It is a dilemma to tick "yes" or "no" as to whether a young child has a disability. This has been a problem for our service. Now we just see a child. See where that child is at. We fill in the report saying these are the needs that presented but that standardised tests were not practical (where they are not). I suppose that gives us some cover..... We have had team discussions and the Assessment officer has come out and talked through this approach with us ..... We have pretty good early intervention services here and we get kids into intervention quickly, which I think is the important thing."

### Senior Speech and Language Therapist - Early Intervention Team

"No it is not a problem at all for Speech and Language Therapists. I can see why it would be more problematic for Psychologists. We just profile the needs and write the report in such a way that you convey that these are the needs that present at this moment in time and that recommend further assessment to rule out underlying conditions should be done as part of intervention."

Teams that developed a degree of comfort around the language of the Disability Act tended to be located in areas where there was good integration of services. The relationship between integrated service provision and the statutory assessment of need process is discussed in Chapter 3. It appears that early intervention teams who are confident of linking children in with their own service, or one which they had a good relationship with, are more likely accept that the statutory assessment of need can be a profiling of need at as point in time. Conversely, clinicians who work in areas where service provision is fragmented between organisations with diagnosis-based entry criteria, feel they cannot meet their duty of care to children in need of service unless their assessment meets (where appropriate) the requirements of the organisations operating in their area.

The implications of assessing need without determining whether a child has a disability as part of a statutory assessment of need are different for school-aged children/children about to enter school and younger children. This issue is discussed below in section 8.3.

#### 7.4.1 Role of assessment officers in making a determination of disability

Assessment officers observed that they, and not the assessors, determine whether or not a child has a disability under the Disability Act. As assessment officers don't carry out assessments they are very much reliant on the information that they receive from assessors. Some assessment officers interviewed for this process had a clinical background and others did not but whether or not they had a clinical background the nature of the role of assessment officers meant that they took responsibility for the determination of disability on the basis of information supplied by others. In and of itself the issue of assessment officer determining whether or not a child has a disability under the Disability Act 2005 is not so problematic. However, when one considers this in combination with the variation in assessment practices that exist across Local Health Office areas it is clear that some assessment officers are in fact in very different positions to other. The following quote illustrates this point:

### **Assessment Officer**

"Young children here get a quick play based assessment. The teams don't use any standardised assessment tools. I take their report, which is usually a few pages, and I make the determination. The system overall here works fairly well. But I am well aware that many of my assessment officer colleagues are getting uni-disciplinary assessments, all based on standardised tools; that the majority of children are coming through AON have 30 page psychology reports; and, that they have a big thick files from across the disciplines. Who is right and who is wrong? I know that they are on much safer ground legally than I am on. I think we need some policy directive, based on consultation with the professionals bodies which says, "this is the minimum required", "if an AON includes x, y, z it is an acceptable minimum standard". Until that happens I think Assessment Officers and assessors will worry about whether what we are doing covers us legally"

## 7.5 Absence of feedback mechanisms

A number of assessors raised the issue of the adequacy of the guidance on conducting statutory assessments of need particularly in relation to the lack of clarity on what constituted an adequate assessment for the purpose of the Act. Essentially, they felt it was left entirely up to the professionals themselves. They also indicated that there was a lack in not having a structured feedback on the quality of the assessments they had carried out and reported on. Some typical feedback in this regards was:

#### Senior Occupational Therapist – Early Intervention Team

"In the beginning I used to do rather long reports on the assessment. I then changed to doing just summary reports. No one commented either way on the reports I produced. It would be helpful to get feedback...there is no feedback from within the Health Service Executive...and it appears the whole emphasis has been on meeting the statutory deadline and not on the quality of the assessment and adequacy of the report".

#### Speech and Language Therapist - Community based

"We haven't had a team discussion on what is an appropriate AON ever, or certainly not since it first introduced. It would be useful to get refresher information and have refresher training sessions. AON does throw up issues that other assessments don't. Having a forum across the whole LHO, or even just within your team, where people talked through how they approach an AON assessment, the challenges it threw up and how they dealt with them would be very useful."

### Senior Speech and Language Therapist – Early Intervention Team

"When I started doing AONs I wrote reports of 4 or 5 pages for every child. It took up a lot of time. I went to the assessment officer and spoke to her about what was required and now I just write the pertinent information in a few bullet points from my notes. I just identify needs as they present on the day and outline what should happen for the child in the future in my opinion. I know lots of colleagues are still writing long reports and caught up in the language on the forms. Someone needs to go around to teams and say this is all you need to do, if you do this you will be covered. That has never happened here".

The key aspects relating to feedback are:

- Whether assessors' reports are adequate and fit for purpose
- Whether assessors' reports are too comprehensive
- Whether assessors' reports are intelligible to parents (or relevant professionals)
- Whether assessors' reports are useful to parents (or relevant professionals)

The exception to this was one Local Health Office area where assessors said that the local assessment officer came out to their team meetings periodically and talked through what was and was not required in a statutory assessment of need report. At such meetings feedback was also given on whether reports the team had submitted lately were giving to much or too little information and answered questions relating to recent examples of statutory assessment of need reports. The teams indicated that these sessions with the assessment officer had very significantly contributed to the teams developing a comfort zone around conducting the statutory assessment of need reports. The relevant assessment officer noted that some of her assessment officer colleagues would not approve of an assessment officer taking such a proactive role as they viewed the independence of the role very differently.

In addition to this particular Local Health Office area, assessors in some other Local Health Office areas did say that their assessment officer was always willing to provide them with advice and feedback. However, in some other areas this informal feedback channel did not appear to exist.

The above raises interesting questions:

- Do assessors need an ongoing feedback mechanism on the requirements of the statutory assessment of need process?
- Would a feedback mechanism contribute positively towards a more consistent approach for assessors conducting a statutory assessment of need?

• Should local assessment officers be the persons who organise ongoing feedback for assessors? Would this role compromise assessment officers' independence? If so, who would be appropriate to perform this role?

The fieldwork conducted would suggest that the answer to the first two questions above would appear to be "yes" on the basis of the evidence gathered but an answer to the third question was beyond the scope of this report.

## 7.6 Resources

Many assessors and assessment officers mentioned that gaps in personnel had huge implications for the statutory assessment of need process. Professionals emphasised the impact of the embargo on public sector recruitment. This was seen as a particularly acute in relation to the filling of temporarily vacant posts arising from the lack of cover for statutory leave - such as, maternity leave, sick leave, parental leave.

The timelines set down in the Disability Act and associated regulations are very tight. If a team member or other colleague is absent for a period, the timelines are problematic and can become untenable. Frontline therapy posts were to have been protected from the embargo on recruitment in the public sector but a recruitment pause announced by the Health Service Executive in July 2011 does apply to frontline therapy posts<sup>38</sup>. Interviewees indicated that gaps in staffing were a major issue in meeting the statutory assessment of need timelines when:

- there were delays in replacing personnel
- where there was a lack of cover for absences (for example maternity leave, sick leave, parental leave)
- when some posts were not being filled

Personnel shortages are affecting the whole of the public service at the moment but interviewees indicated that there are specific features of the statutory assessment of need process which make it unique.

**Firstly**, clinicians coming into a post which involves working within the statutory assessment of need process are often faced with waiting lists, some of which are subject to statutory timelines.

**Secondly**, most clinicians working within the statutory assessment of need process have in effect two referral lists. One governed by statutory timelines and one that is not. Therefore, a clinician coming into a vacated early intervention / children's services post may have to get to grips with assessment governed by the statutory timelines at the expense of the assessment or intervention of those that are non-statutory.

<sup>&</sup>lt;sup>38</sup> Minister for Health, James O' Reilly T.D., written answer to Dáil Query, Wednesday, 19 October 2011; http://debates.oireachtas.ie/dail/2011/10/19/00122.asp

**Thirdly**, many referrals to the statutory assessment of need process are a direct result of personnel gaps elsewhere in the system. The quote below is representative of views expressed by interviewees, particularly those in Local Health Office areas with less integrated or coordinated structures.

## Principal Senior Speech and Language Therapist - Community Based

"We [Speech and Language Therapists] are probably responsible for the majority of AON referrals. Most of the time what we need is a psychologist to see the child to rule in/out an underlying condition. There is a 27 month waiting list to see a community based psychologist here. We just don't have the psychology resources in the community. If we go the AON route the psychology assessment probably won't be done in the timeframes but it will get done in 9 months or a year. The difference between 9 months and 27 months is a massive in the context of a young child".

## 7.7 Timeframes

An opinion shared by some interviewees was that the timeframes set down in the Disability Act and associated regulations hinder good clinical practice and that they are not sensitive to the complexity of certain assessment situations.

The timeframes are seen as hindering good clinical practice because they can force clinicians to make sub-optimal choices. The two quotes below explain how this can happen.

## Senior Speech and Language Therapist - Community Based

"When I am assessing a child who has needs in more than one area, I typically like to talk to my colleagues in the other disciplines involved to have a holistic picture of the child. With AON I have often had my own assessment done but haven't spoken to the other professionals because they may or may not have seen the child. Then I get a call from the Assessment Officer saying she needs my report. I think it is wrong to write a report on a child without hearing the other professionals' views but that often happens in AON cases".

## Senior Clinical Psychologist – School-aged Team

"As part of query Autism assessments I usually try to do a joint session with the Occupational Therapist. That is best practice. But for AON the timeframes are usually so tight that the Occupational Therapist and I can't get a suitable date for a joint assessment, so we do our individual assessments".

The issue of how to deal with assessing children who have quite complex needs and, for whom a quick pre-intervention assessment may not give a clear picture of needs, was dealt with differently in different organisations / locations. The two quotes below indicate the differences in approach.

#### Senior Occupational Therapist – Early Intervention Team

"When we get in a very complex case or a query autism case we don't rush them whether it is an AON or not. It is not appropriate. You need to give young children a chance to see how they will react to a little bit of intervention. Where it is necessary we let the Assessment officer know that we will need an extension..... We are well set up for early intervention here and we have good relationship with the assessment officer. I know that the issue of AON for children with complex needs has been very difficult in other parts of the country".

## Senior Clinical Psychologist, working on a school-aged team and seeing children under 5 of age as part of a private practice

"I do a lot of autism assessments. The timelines are really tight. You are making a determination in very short space of time. In the back of your mind you are thinking that this assessment could end up in court one day. But we are under pressure from managers to meet the statutory timeframes and our managers keep telling us that they are under huge pressure to meet the statutory timeframes".

The issue of what learning the system gets from data collected on statutory timeframes was also raised.

#### **Assessment officer**

"We beat ourselves up about the absolute number of overdue assessments. But what does that figure tell us. I know some Local Health Offices areas have made huge progress but all that get reported on is the absolute number of overdue assessments. One Local Health Office area halved the number of AON overdue one year, but all that is reported on is the **absolute number** of that overdue. If we were interested in learning we would report on **progress** made in tackling AON overdue and the profile those areas that have made progress to learn how they did it.

I could also tell you the background to every single overdue or extended AON that we have on our books at the moment. I could tell which are the result of poorlyorganised, poorly-managed teams, I could tell which are late because of Child and Adolescent Mental Health Service's waiting lists, which are late because of the child has very complex needs and requires very specialist assessments, which are late because the family is so dysfunctional they don't make the appointments. That information is not reported anywhere. To my mind, that is the information that is needed to improve the system".

## 7.8 Statutory assessment of need and families who require mainstream family supports

A number of Assessment officers and assessors raised the issue that the dysfunctional circumstances of some families made conducting statutory assessment of need difficult for three reasons:

- 1. The statutory assessment of need sessions were missed by families, sometimes without notice or explanation, which added more pressure to meeting statutory deadline.
- 2. Assessors in some cases found it difficult to separate out family circumstances or context from disability and felt that the statutory assessment of need process was only concerned with disability-related issues. A typical example of this was where a Physiotherapist or Speech and Language Therapist sees a child and gives the parent some routines to work on. At a subsequent session the therapist's sense is that the routines have not been worked on at home. Therapists found that relating a delay to an underlying condition is made even more difficult in such circumstances but that is what they felt that Disability Act required of them.
- 3. Some assessors and assessment officers indicated that in the course of engaging with the family during the course of the statutory assessment of need process it became clear that family life for the child was chaotic<sup>39</sup>. They felt that in these circumstances a mainstream family services assessment should form part of the assessment process but in most instances<sup>40</sup> it was felt that statutory assessment of need didn't provide for such an assessment.

## 7.9 Administrative workload in the role of the assessment officer

Parents interviewed for this project were overwhelmingly complimentary about the support and guidance they had received from the relevant assessment officers. In some areas the assessment officers were held in extremely high regard by assessors and were viewed as "making the assessment of need process work", while in others areas the role of assessment officers was seen as not as significant.

In some areas assessment officers met all those parents enquiring about the statutory assessment of need process in person, discussed the process with them, and gathered basic information in a systematic way about the child's strengths and needs to inform the subsequent assessment process. In other areas, the assessment officer played a very active role in coaching assessors as to the requirements of the Disability Act and in providing feedback to teams conducting a statutory assessment of need.

<sup>&</sup>lt;sup>39</sup> Assessors were very clear of their obligations in relation to circumstances where they had reason to believe that the child was at risk of abuse. They indicated that they were less clear in relation to children from "chaotic" or "dysfunctional" families

<sup>&</sup>lt;sup>40</sup> As part of the fieldwork for this report one example of where an assessment officer had requested an assessment by a mainstream family support provider **as part of a statutory assessment of need** was identified.

Assessment officers agreed that most of their workload (many stated that up to 80%) was taken up with very routine administration related to the assessment of need process.

Consideration may need to be given as to what is the best use of assessment officers time. Should it be an overwhelmingly administrative post? If so, who should take on the role of shaping or refining the process in a Local Health Office area?

## 7.10 Determining eligibility for assessment under the statutory assessment of need process

The majority of assessors interviewed indicated that children who do not have disabilities, children whose needs are comparatively minor and children who do not have needs for health services (but who may need education services) do regularly get assessed as part of the statutory assessment of need process. Many assessors believed that there needs to be some sort of initial screening in order to determine the most appropriate pathway for the child before a full statutory assessment of need process commenced.

Some Local Health Office areas that were part of this study have developed some means to screen children who do not appear to have a disability at the point of application and children who do not appear to have a need for a health service. However, these practices were not common across the 8 Local Health Office areas which were studied as part of this project.

## **Assessment Officer**

I personally see every applicant. I generally see them in their own home. The purpose of the visit is to gather information not captured in the application. When you have worked with children with disabilities as long as I have you can tell within a few minutes when a child does not have a disability. I have developed a template of my own to capture basic developmental information from the parents. Where this template is flagging that the child does not have a disability I talk to the parent, I talk to the professional who referred the child to the AON and I try to direct them in what I think is the appropriate direction for that child. I always say to parents that they can reapply at any stage. Obviously, the application is only withdrawn if the parents consent. I am conscious of the fact that someday some parent may say that I advised them to withdraw their AON application when in fact they should have proceeded with it. But I against that I don't think its appropriate or in anyone's interest for a child who does not have a disability to be going to the AON.

#### **Assessment Officer**

The issue of referrals from schools is becoming a huge issue. I get a lot of calls from schools and lots of our referrals nowadays are effectively from schools. Teachers have children in the classroom who need a NEPS assessment and if they can't get one they think they will get a psychological determination from an AON. The principal psychologist is now reviewing the information which accompanies the application form and where he determines that the child needs a NEPS assessment he is referring to NEPS closing the AON application on the basis of the application form. Where parents or some of the other therapists make a big enough fuss the psychologist will allow the child through but it is a messy situation.

## 8. Range of related issues

## 8.1 Understanding of the purpose of the statutory assessment of need - variance across Local Health Office areas

The statutory assessment of need process has been embedded into different service configurations in different Local Health Office areas. This has led to quite a degree of variance in the how the process works. This is discussed in detail in Chapter 4.

This variance over time appears to have led professionals, who may or may not be those who carry out statutory assessments of need, to think of the statutory assessment of need process as having different purposes.

The three most common purposes identified by assessors and also by parents were:

- a means to access specialist disability services for those who don't meet the eligibility criteria for such services
- a means to access supports within the education system
- a means to expedite a specialist assessment for those who would not ordinarily be a priority case for such an assessment

The statutory assessment of need process, by and large, is seen as a pre-service, eligibility-determining clinical assessment for those who cannot otherwise prove their eligibility for services.

#### Speech and Language Therapist – Community Team

"I suppose we have come to see AON as a backdoor to services. It is a way of getting a quick assessment for those who need an assessment to get into a service. I am not sure if we are looking at it correctly. Perhaps we are looking at it incorrectly. Perhaps what we need is some guidance on what the purpose of AON is supposed to be"<sup>41</sup>

In a minority of the areas, professionals appeared to have developed other de facto purposes for the statutory assessment of need process. These include:

- the statutory assessment of need process is a means to case manage all children transitions from one service system (for example in the transition from early intervention to school-aged disability services)
- the statutory assessment of need process is a means to ensure that all children who are currently **within** a service receive a multi-disciplinary assessment

<sup>&</sup>lt;sup>41</sup> In these direct quotes LHO refers to local Health Office area; AON refers to the statutory assessment of need under Part 2 of the Disability Act; Non-AON refers to all other type of assessments; NEPS refers to National Educational Psychological Service

## 8.1.1 Understanding of who should get a statutory assessment of need - "children in services don't need a statutory assessment of need"

One of the more surprising findings of this project is that the perception that children in disability services did not require a statutory assessment of need. This is an understanding that has developed in many areas. One possible explanation for this is that the existing service configuration and entry criteria have probably meant that there was less engagement with the statutory assessment of need process.

A finding of this report is that this pragmatic practice appears in some areas to have become quite embedded in people's thinking about the statutory assessment of need process. The quote below is typical of what was heard from a number of professionals involved in the statutory assessment of need process:

"Children in services don't need an AON. Why would you put a child with Down Syndrome through the AON? There is no issue with them getting into services and they will receive supports in school".

## 8.1.2 Implications of emerging or de facto purposes of the statutory assessment of need

These are some macro-level issues to consider if one accepts - or ideally can further verify - a number of findings raised in this report, including

- that the statutory assessment of need process has become primarily a pre-service, eligibility-determining clinical assessment for those who cannot otherwise prove their eligibility for services
- that about 50% of eligible children apply for a statutory assessment of need
- that the number and profile of children with disabilities applying for a statutory assessment of need varies, and that variation is in part related to the configuration of health and education services in a given Local Health Office area

Part 2 of the Disability Act 2005 was seen as a means of providing a tool for service planning and in particular as a tool for highlighting gaps in service provision. Given the points made above, it is difficult see how this objective can be met without a change of direction. The aggregate data gathered as part of the statutory assessment of need process, and reported on in the Section 13 report, will be impossible to interpret meaningfully until those children who are receiving services but referred by another route are brought within the statutory assessment of need process.

Again, if one accepts the points made above, it appears to implicitly endorse a view that those who are in a service (and their families):

- are satisfied with that service
- don't have areas of unmet need
- don't have issues with coordinating their service with non-health funded services
- don't have preferences for a different mix of supports

The above comments are not intended as a criticism of those who currently operate the statutory assessment of need process, as they have merely responded to the current demand for assessment under the Disability Act 2005.

## 8.2 Understanding of what assessments must be included in the statutory assessment of need process

The issue of what assessments have to take place within the statutory timeframes appeared to be treated differently across services and in different locations.

Some teams indicated that assessment officers, on the basis of information gathered and a conversation with parents, indicated that an assessment needed to be conducted across a whole range of disciplines. Assessors, in such circumstances, indicated that they often ended up assessing children who they felt had no needs in their area. In other Local Health Office areas the arrangement between assessment officers and teams was that teams, on the basis of an initial meeting with the parent and child, decided the two disciplines that would perform the statutory assessment of need (or other assessment for service eligibility).

Similarly, some teams and services indicated that where their initial assessment indicated that where further more specialised assessments were required they put this need for further assessment(s) in their report as a recommendation for what the child needs. Other teams and services indicated that "all assessments required to identify **all** of the child's need at this point had to be done within the AON timeframes".

**The Assessor Guidelines** deal with the issue of additional assessments. There does not appear, however, to be a uniform understanding of what assessments should be deferred and take place outside the statutory assessment of need timeframes.

## 8.3 Assessment versus diagnosis for children under 5 years of age and over 5 years of age

Chapter 4 of this report highlighted the variation in interpretation of what is required of a statutory assessment of need. It noted that services in some Local Health Office areas have moved to an understanding that an initial needs-based assessment would be adequate **despite the difficulties which the language of the Act presents.** Assessors working with school-aged children, however, were very clear, that the resource allocation system within the schools system means that anything less than an assessment or programme of assessments aimed at establishing a diagnosis would be inappropriate for school-aged children.

The experience of assessors working with school-aged children is that the resource allocation rules of the service system, which children need to enter, has a critical bearing on the assessments that assessors will carry out. The following quotes are representative examples of this view:

## Senior Clinical Psychologist – School-aged Team

"I don't have a problem with the "nature and extent of disability" section of the report in the sense that I regard it as superfluous. I do have problem with assessment of need not requiring a diagnosis. Yes, every assessment process moves from documenting concerns to formulating a diagnosis. I have tried to do an AON reports on the basis of initial observation and screening but parents weren't very happy. The Irish education system is driven by diagnoses and labels. Parents will be completely frustrated by an AON report for a school aged child without a diagnosis".

### Senior Clinical Psychologist – school-aged team

"Resources for school aged children are driven by diagnoses. If I see a child and profile his or her needs but do not give a diagnosis they won't get any resources at all. A child with a label of ASD will get 5 resource teaching hours a week. If I profile the same child's needs that child will get absolutely nothing. If I delay a diagnosis for that child because I don't think the family is ready all I do is ensure that that child will be without supports in school for longer. Parents of school aged children demand a diagnosis and understandably so.

It is fine for my colleagues in the early intervention team to delay a diagnosis, give a child time and work with the family over time. For them a needs-based assessment works. But I can't send a parent off to a school or to the SENO with a needs profile that will get them no support. That would be unethical".

## 8.4 Practicality of completely "independent" assessments

The Disability Act 2005 states that assessments are to take place without consideration of, "the cost of, or the capacity to provide, any service identified in the assessment". Assessors did find this challenging and there appeared to be some vagueness in how this worked in practice. The following quotes represent some of the comments of operating this aspect of the legislation:

#### Senior Occupational Therapist – Community based

"A challenge of the assessment report is to recommend what cannot be given. It is hard on parents and on therapists to put down on paper what the child needs but also tell the parent what service the child is likely to get in reality".

#### Senior Occupational Therapist – Early Intervention Team

"I know that an AON assessments means that you are supposed to identify support needs and quantify these. But in reality it is about fitting children into best possible solutions that are available in the locally existing services".

#### 8.5 Assessment versus intervention

There were two major issues for a lot of assessors in relation to statutory assessments of need and intervention. These were:

- 1. The implications for their intervention work which as a result of their commitments to the statutory assessment of need process.
- 2. That statutory assessment of need typically did not take place within a context of an intervention programme.

The first point raised above is discussed in section 7.3, which notes that assessors did not in fact commit more person hours to the statutory assessments of need when compared to other similar assessments (for example, assessments for service eligibility).

Some examples of how statutory assessments of need are incorporated into an intervention programmes are discussed in Chapter 5. However, the examples discussed in Chapter 5 are not representative and many assessors find themselves conducting assessments in circumstances which they feel are inappropriate.

## 8.6 Governance and performance monitoring

As mentioned in 7.3, there was a lot of variation in how long it took assessors in the same discipline to conduct a statutory assessment of need. The individual assessors took the same of amount of time to conduct a statutory assessment of need as they did to do other similar assessments. Many of the assessors interviewed, who were part of organisations or teams who had made changes to improve their statutory assessment of need completion timeframes and reduce their other waiting lists, referred to instructions from management to do so. The following quote is representative of this:

#### Senior Speech and language Therapist

"Management here said that all our AONs are to be done on time. As a team we felt we couldn't just tackle our AON times without also working on our EIT waiting list. We discussed it as a team and the solution that we came up with was the multi-disciplinary assessments for all children. Holding multi-disciplinary assessments days was our idea but the pressure to come up with a system which allowed us to complete AONs on time definitely came from management here".

Other assessors mentioned that they were allowed to allocate a block of time to an initial assessment. They allocated the same amount of time to both the statutory assessment of need and to the other assessments. They were also allowed to allocate a second block of time where necessary based on their judgement. If further assessments were required these were to be listed as recommendations for further services and not carried out as part of the initial assessment. Such prescriptive directives from local management appear, on the basis of the fieldwork conducted for this report, to be rare.

Some assessment officers noted that some teams always had them completed within the statutory timeframes, while others were typically late. Some Assessment officers reflected that some teams and services appeared poorly managed and had little or no scrutiny in terms of caseloads or oversight. They made these observations from their experience of being only involved in one aspect of a teams' or services' work.

### Assessment officer

"Information Management Systems that look at caseloads across areas, across teams and for individual clinicians exist. They allow managers to know exactly what clinicians are spending their time on. They would allow managers to show a team that they were taking significantly longer than others to do similar tasks. But there is no appetite for this sort of approach here."

This view that some teams and services lacked obvious management and performance accountability mechanisms was raised by a small number of assessors too.

## Senior Clinical Psychologist, working on a school-aged team and seeing children under 5 as part of a private practice

"From what I have seen since I arrived here is that lots of clinicians write their reports like they are university case studies. That is not appropriate in the public service, it is a luxury that we don't have. We are all public servants, we have an obligation to all the children in our area, which means you have an obligation to do your assessments in a timely fashion and get on with your intervention. It is a manager's job to get people to perform like that. How are clinicians managed in Ireland?"

The above perhaps is more of a general service delivery issue and not an issue for the statutory assessment of need process per se. The specific issue for the statutory assessment of need process is whose responsibility, if anyone's, is it to notice and address if two clinicians / teams consistently take very different amounts of personhours to complete a statutory assessment of need?

## 8.7 Understanding of who should do the statutory assessment of need – the roles of Child and Adolescent Mental Health Services, National Educational Psychological Service and Voluntary Agencies

In the majority of the Local Health Office areas covered by this project there was some level of understanding and some working relationship between Health Service Executive administered services and services provided by Health Service Executive voluntary agencies in relation to the statutory assessment of need process. However, in one Local Health Office area assessors claimed that the voluntary agencies in effect refused to do any statutory assessment of need.

Coordinating structures or informal arrangements between the statutory assessment of need process mechanisms and Child and Adolescent Mental Health Services varied significantly across Local Health Office areas:

• Child and Adolescent Mental Health Services personnel took part in some referral forums for all disability referrals (statutory assessment of need referral and others)

- Child and Adolescent Mental Health Services personnel took part in an Autism Forum (statutory assessment of need referrals and others) in one area
- In one Local Health Office area, Child and Adolescent Mental Health Services were said to "do a statutory assessment of need just without any regard to the timelines"
- In other areas, Child and Adolescent Mental Health Services were said to "refuse to assess children referred from the statutory assessment of need process"

Fieldwork for this report did not find any examples of where statutory assessment of need process mechanisms and the education authorities had developed local protocols or informal arrangements to determine who should assess which children. Responsibility for who should assess school-aged children, who primarily require school based supports appeared to be unresolved and most interviewees for this project indicated that the statutory assessment of need process was open to abuse from schools. In such cases, schools found that they could supplement their National Educational Psychological Services allocation with a statutory assessment of need under the Disability Act.

## 8.8 Reviews of statutory assessments of need

Until recently none of the 8 Local Health Offices consulted for this report had been performing reviews of statutory assessments of need unless requested to do so by parents.

One of the Local Health Offices had recently commenced a process aimed at reviewing all statutory assessment of need files. A template used for reviewing all young children in services in the area had been slightly adapted and approved by the local Assessment Officer as being sufficient to meet the requirements of the Disability Act 2005. This meant that statutory assessment of need reviews should only involve a minimum amount of work over and above that which is normally done in accordance with good practice.

## 8.9 HIQA Standards for the Assessment of Need

Compliance with the Standards for Assessment of Need adopted by Health Information and Quality Authority did not form a major part of this report as an audit of compliance with the Standards was already underway during the period when fieldwork for this report was being conducted.

However, interviewees for this project were asked about the role the Standards played in shaping their approach to statutory assessments of need. Many interviewees indicated that they were not aware of the content of the Standards, while others indicated that the Standards were too general to have much practical application on how statutory assessments of need were conducted.

## 8.10 Statutory assessment of need guidance and templates

As part of the fieldwork for this report the National Disability Authority requested a sample of anonymised completed statutory assessment of need reports and discussed

the report template with assessment officers<sup>42</sup>. Assessment officers were generally of the view that the assessment report template developed by the Health Service Executive is relatively easy to complete.

The Health Service Executive has produced two guidance documents:

- Assessment of need under the Disability Act, 2005 Guidance for Assessors
- Assessment Officers Process and Practice Guidelines

Some interviewees for this report indicated that the guidance had brought clarity to the work that they undertook as part of the statutory assessment of need process. In particular assessors in some areas mentioned that guidance on key terms used in the Disability Act, 2005 had enabled them to better understand what the requirements of the Act meant for their clinical work. However, many assessors drew attention to the fact that they were unclear about the legal status of the guidance that had been provided.

## 8.11 Some practical local issues

There is a range of practical issues which some personnel involved in statutory assessment of need process highlighted in relation to improving the process.

## 8.11.1 Encryption

Assessment officers spent a huge proportion of time photocopying as the process largely remains paper based. In many of the Local Health Office areas interviewees discussed the need for a system to encrypt all reports and forms to minimise the administration burden associated with the paper based system. One Local Health Office Area had received funding and was in fact implementing such an encryption system in 2011. It may be worth further investigating the possibility of developing an encryption system that could be used by all agencies involved in the statutory assessment of need process in all Local Health Office areas.

## 8.11.2 The administration of the statutory assessment of need reports

When discussing the breakdown of workload for a statutory assessment of need and other similar assessments it became clear that assessors spend a very significant amount of time physically writing up reports (separate from the time taken to conduct assessments). In some cases, this report writing phase took "one to two days" in the case of one Occupational Therapist and "one to one and half days" in the case of one Senior Clinical Psychologist.

A subsequent interviewee (also a Senior Clinical Psychologist) who worked for the Health Service Executive and in private practice (but doing work for the Health Service Executive) indicated that dictation services were available to the private practice but not within the Health Service Executive. It was noted that it would take 20 minutes to dictate a report that would take 2 or 3 hours to type up.

<sup>&</sup>lt;sup>42</sup> Assessment officers not assessors complete the statutory assessment of need reports

### 8.11.3 Software for calculating assessment of Autism

Similar to the point made above a Senior Clinical Psychologist who worked for the Health Service Executive and in private practice (but doing work for the Health Service Executive) indicated that in private practice software to score a standardised test was available but that it wasn't in the Health Service Executive. Having tests scored by software took about 2 minutes but to do by hand took about 2 hours.

These points noted raise questions about how scarce clinician hours are used in publicly funded system. Again, this raises issues beyond the statutory assessment of need process per se. However, as scare resources do impact on the statutory assessment of need process they do need to be noted in this context.

## 9. Parents' experiences of the statutory assessment of need

### 9.1 Parents' experiences of the statutory assessment of need process

As part of the fieldwork for this report the National Disability Authority interviewed 33 parents from across the 8 Local Health Office areas. Children of all the parents interviewed had been fully through the statutory assessment of need process. Parents were asked a number of open ended questions relating to;

- their prior knowledge of the statutory assessment of need process
- their referral to the statutory assessment of need process
- their expectations of the statutory assessment of need process
- outcomes for their child and family from the statutory assessment of need process

## 9.2 Prior knowledge of the statutory assessment of need

Parents with few exceptions were found to have very little knowledge of the statutory assessment of need under the Disability Act prior to being made aware of the process by an education or health professional. Of the parents interviewed for this study there were no exceptions to this. However, a few assessors and assessment officers did say that a very small number of parents, who were typically members of a local parent group linked to a local service, requested a statutory assessment of need without being referred by a health or education professional.

The quotes below are typical of the overwhelming majority of parents interviewed for this process.

"No I knew nothing about the assessment of need. I knew nothing about disability. I knew nothing about how disability services worked. But sure why would you, until you realise that your child has needs"

"No didn't know anything about it about it all. I had never heard of the assessment of need, never heard of the Disability Act. It was just that Speech and Language Therapist said that the assessment of need would speed things up for us".

"Family members of mine have children with special needs so I would actually be pretty familiar with disability services around here. But I had never heard of the Disability Act or the assessment of need. People just don't know about it".

For a **minority** of parents this lack of public awareness was an issue, as they felt that they would have requested a statutory assessment of need earlier in their child's life if they had been made aware of it. However, the **majority** of parents were simply glad that the relevant professional had brought to their attention their right to a statutory assessment of need to their attention. "No we knew nothing about the assessment of need. It should be flagged much earlier. It should be flagged at ante-natal classes. I should be in all Public Health Nurses training. 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. From what I can see there doesn't seem to be any system to ensure that young children who really need an assessment of need are directed toward the process".

Some parents, particularly those where early intervention services are integrated, tended not to see a major distinction between early intervention services and the statutory assessment of need process. For these parents statutory assessment of need process was seen as an element of early intervention services rather than something separate.

"We got the assessment of need while we were with the Early Intervention Services. We were getting services. Early Intervention mentioned the assessment of need. I went to see the assessment officer. She was brilliant. She just explained that in terms of getting ready for school that the assessment of need might be good for us".

Other parents, typically parents of school-aged children and parents in areas with less coordinated services, were more likely to have come to see the statutory assessment of need process as a way to access some level of services after an initial failed attempt to access services by another means.

"I knew my child was not meeting his milestones. By the age of two I knew for sure that something was wrong. I went to the GP several times and he said he would make appoints with a community Speech and Language Therapist. But nothing happened. The Public Health Nurse saw him at three, he failed his development test and she said that he might be autistic, but nothing happened. I don't understand why some system doesn't kick in as soon as a child fails a developmental screening. We were completely floundering. We went to a private paediatrician. It was the private paediatrician that mentioned the assessment of need. I am still angry that no one in the public system directed us to the assessment of need".

## 9.3 Referral pathway to the statutory assessment of need process

As stated above, parents awareness of the statutory assessment of need process and their decision to make an application to the statutory assessment of need process was very much based on the guidance and advice of professionals. Table 5 below captures the referring professionals that parents mentioned.

Professionals	Numbers of children referred
Public Health Nurse	7
General Practitioner	2
Speech and Language Therapist	8
Audiologist	
Paediatrician	2
Psychologist	
Early Intervention Team	4
Teacher/Principal	5
Private Occupational Therapist	2
Private Psychologist	
Total	33

## Table 5 – referring professionals

The Disability Act 2005 gives all parents / guardians the right to apply for a statutory assessment of need for children who have or may have a disability. This finding would suggest that there may be more scope for professionals in a Local Health Office area to shape an appropriate referral pathway into the statutory assessment of need process than might have appeared heretofore.

## 9.4 Parents' expectations of the statutory assessment of need

In the interviews with parents for this report an attempt was made to clarify what parents wanted from the assessment of need process. In particular, parents were asked which of the following were most important to them:

- establishing a diagnosis of their child's underlying condition
- establishing their child's strengths, weaknesses and needs
- expediting their child's entry to service

Establishing a diagnosis for an underlying condition tended to be an issue for parents when having such a diagnosis was the basis for accessing the services that their child most immediately needed. In particular, parents of school-aged children and children approaching school-age tended to be quite aware that a diagnosis would be required to unlock resources with the education system. In Local Health Office areas, where early years' services were delivered by disability specific services, parents perceived that a specific diagnosis would help their child to access services.

"We wanted a diagnosis. The assessment officer made it clear that we may or may not get a diagnosis but we knew from talking to the professionals, and in particular the psychologist, that services are tied to diagnoses. A diagnosis is the key to getting help for your child".

"Our son doesn't have a specific named disorder. He was recommended for an SNA [Special Needs Assistant]in school but he got nothing. You have to have a diagnosis to get anything in school. We are due a psychology assessment in September and to be honest if that doesn't give us a diagnosis I would be very disillusioned with the whole process".

Conversely, where early intervention services were delivered by integrated teams, parents tended to be less concerned with establishing a diagnosis.

"I just wanted to know what services he needed and what services we were going to get. I wanted a plan of what support was going to be available to us. I didn't care about a diagnosis. It was clearly explained that a diagnosis wouldn't necessarily come from the assessment of need.

"I wanted a picture of his needs. I wanted some sense of what services he was going to need in the future and how available they would be. I was particularly interested or concerned to know what the services would be like when he went to school".

"We just wanted to know what we need to do to help. We wanted to know what areas we would need to service in the future".

Therefore, parents' acceptance that the statutory assessment of need process as a system to establish need but not necessarily a diagnosis appears to be strongly related to the service configuration, and in particular service entry/resource allocation criteria across the health and education sectors.

The exceptions to this identified in the fieldwork for this report were some parents of children with query Autistic Spectrum Disorder, for whom a diagnosis as early as possible was important regardless of implications for service delivery.

## 9.5 Qualitative outcomes for parents and children<sup>43</sup>

Overall parents were generally pleased to get an overview and a sense of direction arising out of the assessment of need process. Many felt that getting a report and oral feedback from a team of professionals gave them a more rounded picture of their child's needs than they would have gotten had they not received had they not received an assessment of need.

"It was very positive and worthwhile experience overall. We didn't get all the services as frequently as we felt that we needed them but it was great to hear what all his needs were and what services we would get".

Most parents felt that if they had not requested a statutory assessment things would have progressed with their child. The intent of the Disability Act may not have been that it could be used to get services quicker than those trying to access services by other routes. However, there is a view among many parents that it did mean that they

<sup>&</sup>lt;sup>43</sup> The fieldwork for this project had no way of objectively measuring outcomes for children or families and does not purport to do so. All this report aimed to do was to report on parents' subjective views of the outcomes from the statutory assessment of need process for their children.

accessed services quicker than they would otherwise have. The explanation for this, discussed in more detail above, is that many children going through the statutory assessment of need process tend not to have a diagnosed disability nor to have conditions or needs profiles which would otherwise make them priorities for assessment. Therefore, getting an assessment across a number of domains is an impediment to accessing services for these children. Hence, the statutory assessment of need process is seen retrospectively by parents as having "moved things on" quicker for their child.

Parents did not perceive "moving things on for their child" as waiting list hopping (as assessors often do). Most parents had simply reached a point where the service / assessment pathway for their child was not clear or where they were advised that such a pathway would be protracted. At this juncture, a professional, that the family were in contact with, suggested the next step could be a statutory assessment of need.

"We were waiting for a speech and language in the community. We were told it could take up to a year and half. We were not happy with that and challenged it. At that point the assessment of need was mentioned. I had never heard of it but it explained to me that it was a way of getting a full assessment and getting into a service".

Parents' experience of the statutory assessment of need process appeared to be strongly related to subsequent levels of service delivery. Some parents who had been through the statutory assessment of need process were quite positive about their experience of the actual assessment process but as subsequent service delivery did not meet their expectations, some wondered whether the process had been worthwhile for them and their child. Again, such experiences were more common in parents of children of school age and parents of children where services are less integrated.

"We had much better services when we were with the early intervention team. We did the assessment of need before he started school but we are on waiting lists for everything now. He has had to repeat junior infants. I am not satisfied with the assessment of need at all. The whole thing has been very frustrating".

"So far it has led to nothing. We are supposed to get more speech and language and they recommended that he get help in school but so far nothing has happened. It is still early days but if we don't get more services out of it I would be extremely annoyed".

Most parents understood the reports that they had received as part of the statutory assessment of need process and were positive about how it was explained to them.

Some parents felt that they had too many appointments as part of the statutory assessment of need process in a short timeframe. Obviously, such comments were based on parents who had a number of uni-disciplinary assessments as part of their child's statutory assessment of need. In some cases these uni-disciplinary assessments amounted to more than ten assessment sessions. Parents who had had such experiences expressed the view that travel and organising time off work were inconveniences that they were happy to endure for their child's sake but that they would have thought more coordination between assessors could have reduced their need to travel to multiple appointments. Other parents felt that so having many assessment sessions in a short space of time was too much for young children.

## **10.** Conclusions

The points set out set below in these concluding remarks need to be considered in light of the findings of this report. Some of these points will require further examination in order to consider how best they can be addressed.

The National Disability Authority would welcome an opportunity to engage with relevant stakeholders to discuss how the conclusions of this report could best be furthered in the interest of improving the operation of the statutory assessment of need process under the Disability Act 2005.

The following issues arose in the course of the fieldwork:

- The deferral of the enactment of assessment under the Education of Persons with Special Educational Needs Act 2004 has resulted in some children with educational support needs being channelled through the statutory assessment of need process. This has brought pressure to bear on assessors to carry our diagnostic assessments under the Disability Act. This is a matter which needs urgent attention
- Perceptions of what is required under a statutory assessment of need are varied. In some cases, the statutory assessment of need is being perceived as "special" and/or in a "rarefied space". It is also clear that the type and quantity of assessments conducted as part of the statutory assessment of need process is not standardised at national level
- The Health Service Executive have issued national guidelines, in relation to the statutory assessment of need. These appear to have had little impact in certain areas. A significant number of personnel, involved in the statutory assessment of need, are of the view that the guidelines have an inadequate legal status and therefore feel they are obliged to carry out assessments in a manner which they believe is required of them by the Disability Act 2005
- HiQA have published standards in relation to the statutory assessment of need but there is no systematic national monitoring of compliance
- Local management by the Health Service Executive is weak regarding oversight and coordination of the statutory assessment of need process in some Local Health Office areas, As a result, there appears to be very little feedback and/or direction on how statutory assessments are being conducted by clinicians
- Assessment Officers have a pivotal role to play in the statutory assessment of need. There are varying understandings as to what that role entails both among assessment officers themselves and among teams they worked with
- It is very evident in Local Health Office areas, that had integrated structures and worked as multi-disciplinary teams, were much better placed to effectively deliver on the statutory assessment of need requirements
- Some areas have developed smart work practices, such as:

- Alignment of the statutory assessment of need process with other assessments being done
- Group assessments and interventions
- Referral fora
- Such practices have enhanced the statutory assessment of need process
- parents are mostly positive about their experience of the statutory assessment of need process. Parents' satisfaction, however, is related to whether or not their child received services or enhanced services after the statutory assessment of need process was completed

The findings of this report indicate that there is no one single solution which will resolve all of the challenges to operating the statutory assessment of need process. Rather they suggest that a number of interdependent changes would allow for a more efficient statutory assessment of need process.

The key interdependent issues, which may contribute to improving the statutory assessment of need process, are the need to:

- develop appropriate instruments to bring legal clarity to various aspects of the assessment process
- further integrate early intervention and children's disability services
- provide assessors with feedback and have enhanced local management of the process
- resolve the incompatibility of the statutory assessment of need process and the resource allocation rules operated by the Department of Education and Skills and the demands being placed on assessors due to deferral in enacting the legislation regarding assessments for children with special educational needs
- implement a range of smart working processes and systems that ultimately would lead to a more efficient use of scarce resources

To make progress in one of these key interdependent issues requires progress on the other key issues.

## 10.1 Legislative requirements to underpin new policy directions

Any proposed developments regarding the statutory assessment of need under the Disability Act 2005 should be considered against the background of the emerging policy proposals from the current Value for Money and Policy Review.

A strong governance framework will be needed to underpin the provision of the supports and services for people with disabilities that is envisaged in this new policy direction.

The elements of such a governance framework<sup>44</sup> include:

- Processes for assessing need
- Processes for allocation of resources
- Processes for procurement and commissioning
- Quality assurance systems, including process for managing risk
- Processes for performance management, review and accountability
- Appropriate information systems
- Management structure

When the new policy direction is decided upon regarding the future of disability services consideration should be given:

- to any proposed changes requiring primary legislation
- to any changes that may be required to assessment of need in Part 2 of the Disability Act 2005 and the accompanying regulations

## 10.2 Provide legal clarity for statutory assessment of need process

The consultation undertaken shows that there are differing views in the system as to what level of assessment is demanded by the terms of the Act, particularly in relation to determining 'the nature and extent of disability'. While the guidance given by the Health Service Executive states that an assessment of need does not require a diagnosis, these guidelines do not have a legal standing, and some practitioners are of the view that they are legally required to give a diagnosis. The area where this is problematic and time-consuming is where the child's diagnosis is not obvious, and where extensive testing over a period may be required (for example, a child whose presenting symptoms may or may not constitute autism).

In these circumstances, there may be merit in bringing greater consistency and certainty to the process via some form of guidance which has a statutory status – examples could be standards, Regulations or a statutory Code of Practice. If such were developed it might aim to:

- underpin the guidance for carrying out assessments
- address legal concerns regarding the definition of disability
- have an agreed descriptive model for functional assessment, with clarity on stated purpose, clearly defined stages and feedback process for assessors
- clarify that an assessment of presenting need, and not a diagnosis, is required
- foster a multi-disciplinary/team approach

<sup>&</sup>lt;sup>44</sup> Department of Health - Expert Reference Group on Disability Policy 2011, **Report of Disability Policy Review,** page 17

The development of any such instrument should:

- be based on good practice and relevant standards
- take account of the views of parents of children with disabilities
- be mindful of any developments emerging from the Health Service Executive's national co-ordinating Group for Progressing Disability Services for Children and Young People

Consideration could also be given to establishing a multi-disciplinary working group as soon as possible to inform the development of any legal instruments. The working group could be drawn from the various stakeholders engaged in the statutory assessment of need process and include both parents and practitioners.

## 10.3 Reconfiguration of services for children and young people with disabilities

Where the Department of Health and the Health Service Executive have configured disability services for children into geographically-integrated teams, the National Disability Authority found that the statutory assessment of need process worked better and in a more streamlined way. There was also less emphasis on using the assessment process to develop a diagnosis in order to meet the specific entry requirements of individual services.

Accelerating the reconfiguration into geographically integrated teams would be very important therefore in improving the efficiency and effectiveness of the statutory assessment of need process.

## 10.4 Ongoing assessment as part of intervention, and reviews under the Disability Act 2005

Ongoing assessment of young children is part of the normal process of intervention, and this is an important form of non-statutory assessment of need for children outside the statutory assessment process. There may be a way to integrate such assessment into a statutory needs assessment process.

The National Disability Authority found that few children had completed a statutory review of their needs. For children who have had an initial statutory assessment, a way of streamlining things could be to integrate the ongoing assessment by their service into the statutory process, to support an efficient system of statutory reviews. The Health Service Executive could examine the scope to achieve this through putting revised processes in place.

## 10.5 Health and education sectors

The Health and Education cross-sectoral team, should commence a number of critical pieces of work to ensure that the interface with the education system does not negatively impact on the statutory assessment of need process.

### 10.5. I Education support should not require a prior diagnosis

The resource allocation rules of supports for children with low incidence special education needs is driving a demand for diagnostic assessments, which assessors feel compelled to conduct.

The National Disability Authority also notes that in the absence of a full commencement of the Education for Persons with Special Educational Needs Act 2004, the assessment of need under the Disability Act 2005 is being used a means to unlock support in the education sector.

The Department of Health and the Department of Education and Skills should advance the implementation of the recommendation of the National Council for Special Education research report that, "a diagnosis should not be a prerequisite or determinant for the allocation of additional resources for a child or young person with SEN" by developing a framework for SEN assessment using an interactionist/ecological model as recommended by the report authors<sup>45</sup>.

The Department of Health and the Department of Education also need to bring clarity to:

- what constitutes an education support
- what constitutes a health support
- what are the appropriate assessment processes for accessing either or both

The National Disability Authority acknowledges the work that the Health and Education cross-sectoral team have conducted to date. However, given the critical importance of the interface between health and education services for young children with disabilities and/or special education need, the National Disability Authority advises that a Task Force to address these issues, reporting to both the Minister for Health and the Minister for Education and Skills, be established and requested to report within as short a timeframe as is appropriate.

## 10.6 Children in vulnerable families

In the context of the fieldwork for this report, issues were highlighted regarding children with disabilities within vulnerable families. Some of the issues related to parents not showing for appointments. There are vulnerable families who lack capacity to engage with providing support to their children, or lack the skills or competencies to do things within the home that would facilitate a child's progress.

### 10.6.1 Cross-linkage with support programmes for vulnerable families

The Programme for Government contains a commitment for the establishment of a Child Welfare Agency. The Department of Health and the Department of Children

<sup>&</sup>lt;sup>45</sup> Desforges, M. and Lindsay,G. (on behalf of the National Council for Special Education) 2010, Procedures used to Diagnose a Disability and to Assess Special Educational Needs: An International Review

should engage, at a strategic level, to ensure that standardised protocols are developed, so that the needs of children with disabilities within vulnerable families can be adequately and equitably addressed.

## 10.7 Referrals and determination of eligibility for assessment

In the course of the fieldwork it became apparent that this was an issue with polarised views. Some professionals held the view that the Disability Act allowed any parent, whose child may have a disability or they were concerned about his/her development, to get a statutory assessment of need. Others held the view that this was an inappropriate channel. They felt there is an onus on the assessment officer to try to determine the presence of a "significant need," based on the evidence they have in the application, prior to proceeding with a full statutory assessment of need. Assessment officers did express concerns regarding this. Some were of the view that the only grounds for refusing an application relate to age and an assessment has been carried out and the period specified in the report regarding a review has not expired.

The Health Service Executive should develop tools and or guidance to support the assessment officers in making the determination of whether a child is eligible or not for a statutory assessment of need under the Disability Act 2005. Such guidance would need to be underpinned by an appropriate legal instrument.

The Health Service Executive should give due consideration to whether tools and/or guidance could be developed to provide a consistency at the first point of contact – typically a professional in the health or education sector – as to whether a referral of a child with an apparent developmental delay for the statutory assessment of need is the most appropriate course of action.

## 10.8 Child and Adolescent Mental Health Services (CAMHS) and the Disability Act

In view of the variation and lack of clarity on the role of the Child and Adolescent Mental Health Services in relation to assessment of need under the Disability Act, the Health Service Executive should give urgent attention to the standardisation of the role of the Child and Adolescent Mental Health Services and its responsibility under the Disability Act 2005.

## 10.9 Feedback to assessors

The Health Service Executive should develop an effective mechanism for ensuring that individual assessors are provided with feedback on assessments they carry out under the Disability Act 2005. The feedback should be focussed on whether or not the individual assessments are optimal for the purposes of the Disability Act 2005. The development of appropriate legal instrument(s), such as suggested above, would bring clarity as to what is and is not required of assessors in conducting statutory assessments of need. Such clarity should enable managers to provide assessors with more consistent feedback.

## 10.10 Improving communications with those involved in the assessment of need process

The Health Service Executive should develop a mechanism for enhancing communications and information flows between all those involved in the assessment of need process. The existing Health Service Executive's web-based forum <http://:www.hseland.ie>could be a suitable forum for such communications. This central point could contain all the relevant materials relating to assessment of need under the Disability Act 2005. This would include, inter alia:

- Guidance
- Procedures
- Protocols
- Reports under section 13
- Sharing good practice
- Questions and answers
- In order to enhance the sharing of good practice, the Health Service Executive should encourage all Local Health Office areas to (re)establish the assessment of need Local Implementation Groups and to encourage assessment of need Local Implementation Groups to document and share good practice through the web portal.

## 10.11 Communication with parents re appointments

While non-attendance at assessment appointments can signal that it is a vulnerable family, there may also be practical issues that affect attendance. A multi-disciplinary assessment is much easier for families to manage than a series of separate single-discipline assessments. Another practical measure may be to communicate in advance with parents around suitable dates and times, and to issue reminders via text message.

## 10.12 Savings

This report found that many professionals involved in the statutory assessment of need process spent considerable periods of time on relatively routine tasks that could, in some cases be more effectively done by other people or by using appropriate technology. Efficiencies could be achieved if the Health Service Executive ensured that:

- all agencies conducting statutory assessments of need have access to IT services and appropriate encryption software. This would facilitate the confidential electronic transmission of documentation and ensure that the entire process can be based on electronic based document system
- organisations and teams provide clinicians with appropriate level of administrative support for functions such as typing up dictated assessor's reports. Such a practice would allow clinicians to devote more time to assessing and providing intervention to children

• organisations and teams have appropriate software to score standardised assessment tests. This would allow clinicians to devote more time to assessing and providing intervention to children

## Appendix I- Schedule of interviews

Activity	Dates
Meeting with Local Health Office area 1 personnel involved	8 June 201 I
with statutory assessment of need process	
Meeting with Local Health Office area 2 personnel involved	13 June 2011
with statutory assessment of need process	
Meeting with Local Health Office area 3 personnel involved	14 June 2011
with statutory assessment of need process	
Meeting with Local Health Office area 4 personnel	15 June 2011
involved with statutory assessment of need process	
Meeting with Local Health Office area 5 personnel involved	16 June 2011
with statutory assessment of need process	
Meeting with Local Health Office area 6 personnel	21 June 2011
involved with statutory assessment of need process	
Meeting with Local Health Office area 7 personnel involved	23 June 2011
with statutory assessment of need process	
Meeting with Local Health Office area 8 personnel involved	27 June 2011
with statutory assessment of need process	
Parent phone interviews	Conducted over
	period June to mid
	September 2011

## Appendix 2 - National Disability Authority questionnaire

#### **Priority Questions Assessment officers**

**1.1.** Background information on the assessment officer, i.e. do they have a clinical background, how long they have been an Assessment officer, etc.

**1.2.** Typically, how do children come to be assessed within or outside the statutory assessment of need process?

**1.3.** Are specific strategies (formal and informal) deployed to "manage" the numbers who apply for assessments under the statutory assessment of need process?

**1.4.** Is there a pattern to statutory assessment of need referrals that is different from other assessment referrals?

**I.4.1** Are different professional involved in referring children via statutory assessment of need?

**1.4.2** Are children with certain disabilities more likely to be referred via statutory assessment of need?

**1.4.3** To what extent have referrals directly or indirectly from the education sector driven demand for statutory assessment of need?

**1.4.4** Is there a difference in the level of information supporting the referral?

I.4.5 Other

**1.5.** When you initially meet parents are they generally well informed about what a statutory assessment of need can and cannot deliver?

**1.5.6** If parents at these initial meetings do have misconceptions about the statutory assessment of need process, what do these misconceptions relate to?

**1.5.7** What efforts do you make to inform parents of what to expect from a statutory assessment of need process (i.e. explain that it won't necessarily lead to a diagnosis)?

**1.6.** What information, if any, do you gather about the child and the family before you refer him to a clinician or service for an assessment?

**1.6.1** Is there a structure to capture this information?

1.6.2 Do you make this information available to assessors?

**1.6.3** Do you have a process / structure for providing assessors with this information?

**1.7.** How do you decide where you send a child to be assessed under the statutory assessment of need process?

**1.8.** Is there a referral forum [or some such structure] to support you in your decision?

**I.8.1** What is the composition of the referral forum?

**1.8.2** Has the development of a referral forum been useful to you in your role? If so, please explain?

**1.9.** How do you decide what needs of the child are to be assessed under the the statutory assessment of need process?

**1.10.** How do you communicate your opinion for what needs should to be assessed to relevant clinicians / services?

**1.10.1** Do you have a sample / anonymised communication to relevant clinicians / services?

**1.11.** Do you feel that children going through the statutory assessment of need process are receiving assessments that are appropriate for initial assessments?

**I.II.I** [If you think they are over-assessed, has anybody locally discussed this with clinicians?

**1.11.2** What do you think could be done to address this?

**1.12.** What role does the level of cooperation between the Assessment officer and the team management / service management play in ensuring assessment resources are used efficiently?

**1.13.** What are the principal causes for the overdue assessment in your opinion?

**1.13.1** Has anything been done to address this issue / these issues?

**1.13.2** What do you feel could address this issue / these issues?

**1.14.** Has / would the integration of early intervention services made / make the operation of Part 2 easier or not?

**1.14.1** (Where there are integrated services): how has the statutory assessment of need been integrated with other business processes?

**1.15.** Do you find completing the assessment report difficult? If so please explain why?

## 2. Service manager / Team leads<sup>46</sup>

**2.1.** Background and context of service (integrated early intervention team, single disability specific service, etc.)

**2.2.** Background and context of referral model in operation (pre-statutory assessment of need process and for children who are currently referred outside statutory assessment of need process) [request copies of any relevant guidance, frameworks, templates]

**2.2.1** Description of assessment model /approach deployed for children referred outside of the statutory assessment of need process

**2.3.** Background and context of assessment model used for statutory assessment of need process referrals [request copies of any relevant guidance, frameworks, templates]

**2.3.1** [If there is significant difference between initial assessments for other assessment referrals and statutory assessment of need process] Why do you have different approaches to the statutory assessment of need process and initial assessments for other assessment referrals?

**2.4.** What is the approximate ratio of children being assessed under the statutory assessment of need process and those receiving services who did not receive a statutory assessment of need? (important to note that in Local Health Office areas where there are multiple services or referral pathways, a manager may only have this information for their own services and/or differences in integrated services)

**2.5.** Is there a pattern to referrals for the statutory assessment of need process that is different from other assessment referrals?

**2.5.1** Are different professional involved in referring children via the statutory assessment of need process?

**2.5.2** Are children with certain disabilities more likely to be referred via the statutory assessment of need process?

**2.5.3** To what extent have referrals directly or indirectly from the education sector driven demand for the statutory assessment of need process?

2.5.4 Is there a difference in the level of information supporting the referral?

<sup>&</sup>lt;sup>46</sup> This refers to line manager of the assessors who carry out the assessments as part of the statutory assessment of need process. It could be a team lead, service manager or clinical lead. The purpose of these interviews is to try to ascertain the extent to which team / management guidance has shaped the manner in which assessors approach the statutory assessment of need.

## **2.5.5** Other

**2.6.** How is it determined what needs of the child are to be assessed under the statutory assessment of need process?

**2.6.1** How the number of domains are identified that a child will be assessed on?

**2.7.** To what extent do you influence how assessment of need process under Part 2 of the Disability Act is operated within your team / service?

For example, how much if any do you influence:

**2.7.1** Which of the child's needs are assessed under the statutory assessment of need process [i.e. are strategies deployed to assess needs in areas where child is exhibiting greatest need]?

2.7.2 The number of domains that a child will be assessed on?

**2.7.3** The intensity of the initial assessments that will be undertaken by clinicians on your team for children referred via the statutory assessment of need process?

**2.8.** What sort of strategies are used to gather information in advance of a team assessment, e.g. review of files; self assessment of parental needs / views; parent interviews; basic screening; conference with existing professionals (heath and non-health) in the child's life? If such techniques are used how do they shape subsequent team actions?

**2.9.** Have the protocols on the intensity of the initial statutory assessment of need process or the tools to be used by the teams been developed locally? Do you have locally developed protocols for the initial assessment of young children referred outside of the statutory assessment of need process?

**2.10.** How parents are included in the statutory assessment of need process under Part2? Is this any different from how parents are included in assessments outside of the statutory assessment of need process?

**2.10.1** [If there is a difference of approach to parental inclusion between the statutory assessment of need process and other assessment processes]. Why do you think there is a difference in approaches to parental inclusion for the statutory assessment of need process and other assessment processes?

**2.11.** What role does the level of cooperation between the Assessment officer and the team management play / service management in ensuring assessment resources are used efficiently?

**2.12.** At a number of fora, where the statutory assessment of need process has been discussed, clinicians have indicated that they feel that language of Part 2 places a legal obligation on them to conduct a very comprehensive assessment akin to an assessment they might conduct where a child was party to legal proceeding.

2.12.1 Has this been an issue in your service?

**2.12.2** Have efforts been made to establish clarity on what are the requirements under Part 2 for clinicians? If so, please describe these efforts?

**2.13.** What approximately is the clinical specialist time needed to complete a statutory assessment of need process under Part 2? (note this information needs to be captured by clinical specialism and, if possible, by disability type)

**2.13.1** How would this compare to an assessment to determine eligibility (outside of the Part 2 framework) of a child for services?

**2.13.2** What specifically about the legislative requirements of the statutory assessment of need process is driving the difference, if any?

**2.13.3** Has your team / service developed protocols on the intensity of the initial Part 2 assessments or the tools to be used by the teams?

2.13.4 Approximately how much of this time is spent on

- I. Actual clinical work.
- 2. Report writing.
- 3. Summary report completion

**2.14.** An assessment under statutory assessment of need process requires that a child's needs are assessed not necessarily that a child or family be given a diagnosis. Does this distinction cause difficulties for your team?

2.14.1 If so, have efforts been made to address this issue?

**2.15.** What are the main challenges to operating Part 2 for your team / service in your opinion?

## 2.15.1 What action, if any, has your service / team taken to address these issues?

2.15.2 What do you think would be required to address these challenges?

**2.16.** Has / would the integration of early intervention services made / make the operation of Part 2 easier or not?

**2.17.** To what extent is the HIQA Standards for statutory assessment of need process integrated in the team's work?

## 3. Assessors

**3.1.** Context and background – profession, years of professional experience, experience of assessment before introduction of the statutory assessment of need process currently conducting assessments from referrals other than the statutory assessment of need process.

**3.2.** Do you typically assess children as part of a team or by a uni-disciplinary assessment?

**3.2.1** Is there a pattern that is different to the statutory assessment of need process referrals from other assessment referrals?

**3.2.2** Are different professional involved in referring children via the statutory assessment of need process?

**3.2.3** Are children with certain disabilities more likely to be referred via the statutory assessment of needs process?

**3.2.4** To what extent have referrals directly or indirectly from the education sector driven demand for the statutory assessment of needs process?

3.2.5 Is there a difference in the level of information supporting the referral?

**3.3.** What sort of strategies are used to gather information in advance of a (team) assessment, e.g. review of files; self assessment of parental needs / views; parent interviews; basic screening; conference with existing professionals (heath and non-health) in child's life? If such techniques are used how do they shape your subsequent actions?

**3.4.** At a number of fora, where the statutory assessment of needs process has been discussed, clinicians have indicated that they feel the language of Part 2 places a legal obligation on them to conduct a very comprehensive assessment akin to an assessment they might conduct where a child was party to legal proceeding.

3.4.1 Has this been an issue in your service?

**3.4.2** Would you assess two children presenting with broadly similar needs very differently if one was referred under Part 2 and the other was not?

**3.4.3** What's your understanding of what constitutes an appropriate clinical assessment, for your clinical specialism, to comply with the statutory assessment of need process under the Disability Act?

**3.4.4** Is it your understanding of Part 2 that you need to conduct a very comprehensive assessment on any child referred via Part 2?

**3.4.5** Have efforts been made to establish clarity on what are the requirements under Part 2 for clinicians? If so, please describe these efforts?

**3.5.** 3.5 The statutory assessment of need process under Part 2 requires that a child's needs are assessed not necessarily that a child / family be given a diagnosis.

**3.5.1** Does this distinction cause difficulties for you?

3.5.2 If so, please explain why this distinction has caused you a difficulty?

**3.6.** Some stakeholders have argued that the requirement of assessment officers to provide a statement of the "nature and extent" of a disability means that in effect assessors must provide a diagnosis. Has this phrase in particular caused you particular difficulty?

**3.7.** Has your team / service management provided you with any guidance / fostered discussion around the difference between assessing need and establishing a diagnosis or around what the phrase "nature and extent" of disability means in the context of Part 2? If so please describe?

**3.8.** Do you have locally developed protocols or guidance for the initial assessment of young children referred via the statutory assessment of need process?

**3.8.1** In particular, have the protocols on the intensity of the initial statutory assessment of need process or the tools to be used by the teams been developed locally?

**3.9.** What approximately is the clinical time you require to complete the statutory assessment of need process under Part 2?

**3.9.1** How would this compare to an assessment to determine eligibility (outside of the Part 2 framework) of a child for services?

**3.9.2** What specifically about the legislative requirements of the statutory assessment of need process is driving the difference?

**3.9.3** Has your team / service developed protocols on the intensity of the initial Part 2 assessments or the tools to be used by the teams?

3.9.4 Approximately how much of this time is spent on

- I. actual clinical work
- 2. report writing
- 3. summary report completion

**3.10.** What are the main challenges to operating the statutory assessment of need process for you?

**3.10.1** What actions, if any, have your service / team taken to address these issues?

3.10.2 What do you think would be required to address these challenges?

**3.11.** Has your professional body produced protocols / guidance specific to the statutory assessment of need process?

**3.11.1** What extent has this guidance shaped your approach to how you conduct assessments as part of the statutory assessment of need process?

**3.11.2** Does this guidance conflict with any guidance on conducting the statutory assessment of need process that you may have been given by your team / service manager/ or the Health Service Executive's National Disability Unit?

**3.12.** To what extent is the HIQA Standards for Needs Assessment integrated into your work?

**3.13.** How are parents included in the assessment of need for the statutory assessment of need process? Is this any different from how parents are included in assessments outside of the statutory assessment of need process?

**3.14.** Has / would the integration of early intervention services or children's services made / make the operation of Part 2 easier or not? If you think so please say what this has / would make a difference

**3.14.3** (Where there are integrated services): how has assessment of need been integrated with other business processes?

## **Appendix 3: Local Health Office area Sample Data**

Anonymised Local Health Office Area	Estimate of number of children with a disability aged 0 - 4	Applications	Started Stage 2	Reports Completed	Milestone Activity	Assessments Overdue
7	495	12	15	2	29	41
2	319	23	2	3	38	42
3	643	27	22	7	56	4
5	657	32	25	13	70	6
4	374	8	7	3	18	0
8	457	4	9	5	28	
	277	19	16	3	38	0
6	399	32	37	24	93	22
Sample Average	452.625				46.25	14.5
National Average	426				42.5	28.4

Source: Estimates in column 1 were supplied by the Health Service Executive and are based on Census 2006 figures and assume a 4% disability prevalence rate. Other figures based on figures supplied by the Health Service Executive's Disability Information Unit and reflect activity to date in 2011

## Appendix 4: Health Service Executive forms and guidance

## Disability Act 2005 Guidance Note No: 29(A) 11<sup>th</sup> August 2010 Section 1 – General guidance for assessors

#### Introduction

This document has been developed by the Assessment Process Working Group established by the National Project Team for the Implementation of the Disability Act. The Working Group brings together management and clinicians from both the HSE and voluntary sector service providers, NDA, NCSE, DoHC, and NEPS.

The aim of the document is to assist assessors when they are deciding on the level and extent of assessment(s) necessary in order for the Assessment officer to be able to provide the applicant with an Assessment Report that meets the requirements of the Act. The document also aims to assist in improving the consistency of interpretation among clinicians of the terms used in the definition of disability contained in the Act.

It is important to emphasise that these guidelines do not constitute a standard of practice and they are not intended to substitute for sound clinical judgment which is a matter for relevant professionals.

The members of the Working Group engaged with the various national professional representative bodies of the disciplines concerned and with practitioners providing assessments and services in a team setting. The guidance included in this document is based on those discussions.

#### **Essential Points To Note**

• The Disability Act gives an individual with a disability the right to an assessment of their health and education needs.

• In relation to health services, the intention of the Assessment of Need process is to identify the health needs resulting from the child's disability.

• It is a matter for clinicians, based on their experience and qualifications, to decide how best to evaluate the needs at that time of the child being assessed. The Act does not give the right to a specific assessment at a particular point in time.

• The Disability Act does not give a right to access to a diagnosis unless it is required at that time to identify the health needs occasioned by the disability.

#### **General Principles Underpinning all Assessments of Need**

• Child and family centred – the Assessment of Need (AON) should be focussed around the child and family, recognising them as individuals and concentrating on outcomes important to them. Information and communication – information should be available in a timely manner throughout the process, and assessors should engage with the family on the process and arranging of assessments.

• Co-ordination – where more than one assessor is involved assessors should coordinate their assessments, in consultation with the Assessment officer. • Outcome-focussed and strengths / needs-based – the purpose of the AON is to identify the needs of the child and family, and to set outcome-based goals which reflect the child's level of functioning in the different areas of development and his or her ability to participate.

• Appropriateness of assessment – the assessment should be appropriate for each individual child and family at the time of assessment and include consideration of the age of the child, culture, presenting difficulties and readiness of the whole family.

#### Assessment Pathway

Once referred for an AON all children should follow a similar assessment pathway.

The pathway proposed involves three stages:

- I. The initial planning stage;
- 2. The actual assessment process;
- 3. Compilation of the report.

## I. Initial Planning Stage

The Assessment officer should clarify with assessors the specific aim and purpose of assessing this child.

The team / assessors should then identify what is required to give a picture of this particular child's health needs, including which disciplines will carry out the assessments and the level and depth of assessments to be carried out. Assessors should be guided by what is normally accepted as good practice in assessment when a child is coming into their service.

Children should be assessed in line with best practice to inform intervention, and assessors should not carry out assessments over and above those clinically indicated. Bearing this in mind, clinicians should judge what level of assessment/s are indicated and may recommend further assessment at a future, and more appropriate time.

In order to make these decisions, assessors whether working in a team or individually, should confer by meeting or by teleconference, using all the information received from parents, existing reports, clinical judgement and the Assessment officer's requests.

In some cases the outcome of these discussions may vary from the original requests made by the Assessment officer. The reasons for these decisions, the clinical judgment on which they are based and confirmation that the decision is not based on resource considerations, must be given to the Assessment officer in writing at the earliest possible opportunity and discussed with the parents and/or guardians.

Lack of resources is not a valid reason for refusing to carry out a specific assessment or choosing one form of assessment over another. If a member of a team is not available for any reason and their discipline is considered necessary for the assessment, alternative arrangements must be made and the Assessment officer should be consulted.

The Disability Act does not require a diagnosis to be made as part of AON. What is required is an assessment of the child's needs at the time.

The child, particularly an existing service user, may have had assessments within the last twelve months. If they were conducted in accordance with the HIQA Standards, these may be acceptable for the purposes of the Assessment of Need and new assessments may not be required. This should be discussed with the Assessment officer who has guidelines covering this issue.

A team should identify one of their members to be the link person to ensure communication with the family and with the Assessment officer throughout the assessment period. Individual assessors should maintain contact with each other and with the Assessment officer.

An assessment plan should be drawn up to include:

• Settings for assessments and any supports required;

- Sequence / co-ordination of assessments;
- Possible times and dates to be agreed in consultation with the family.

### 2. Assessment Process

Parents should be actively engaged throughout the process and all steps clearly outlined to them. These steps may overlap depending on local service structures and practice.

**Step I:** The Assessment officer will have passed on to assessors all relevant information he or she has obtained from the family.

An initial clinical interview by one of the team / assessors with the family will gather further information, get the parents' understanding of their child's strengths and needs and answer questions they may have around the process.

**Step 2:** Assessors interact with the child using formal and/or informal assessments either jointly or individually to form an opinion of the child's strengths and needs. Formal procedures for assessment may include the use of assessment tools or checklists or medical / clinical tests and procedures (Appendix I provides suggested criteria for choosing assessment tools). Informal procedures include conversations with parents, informal observations of the child and other informal assessments as appropriate.

Clinicians are the best qualified and best placed to make the decisions, based on their clinical expertise, about the appropriate methods to use and the extent of assessment needed in order to identify the health needs of the child and the services required. The decision on the level and extent of assessment cannot be influenced by the resources available to the assessor.

At this stage additional assessments may be identified before the process can continue (e.g. Audiological assessment) and the Assessment officer should be informed as early as possible so that arrangements can be made.

**Step 3:** Assessors will agree whether a sufficient picture of the child's needs has been gathered at this time or if further assessment is required. All findings should be shared with parents as dictated by good practice.

It may not be appropriate to carry out all assessments necessary to identify the child's needs at this stage (e.g. the child is too young). In such cases two options are available:

- 1. An extension to the timeline for the assessment process may be negotiated through the Assessment officer;
- 2. An appropriate date for a formal review of the Assessment Report may be specified.

Significant assessments which will identify needs should be conducted under the Act through the Review procedure rather than included in the Service Statement.

Any assessments not necessary for identification of needs (e.g. diagnostic assessment in some cases) may be included in the Assessment Report and arranged as part of the Service Statement. However the reasons for including any recommendations for further assessments need to be carefully considered in terms of their value to the child's intervention programme.

## 3. Report Stage

All assessors involved in the assessment of need process share outcomes and agree joint recommendations and goals. This information will have been shared already with the parents throughout the process. Clinicians may wish to provide parents with a copy of their individual findings during the process. Reports given to parents should be headed, 'This report forms a part of the full Assessment Report under the Disability Act, which you will receive in due course.'

Parents will receive all reports so clinicians should take this into account when considering inclusion of information such as sensitive details about the wider family or matters which they have not discussed with the parents. Reports should not include extraneous material which is not relevant to identifying the child's needs arising from their disability.

Child protection concerns which arise during the assessment should be dealt with according to Children First Guidelines and usual practice within the employing organisation. Responsibility for reporting such concerns should not be delegated to the Assessment officer via the Assessment Report.

A joint final report for the Assessment officer is preferable. (Separate reports may also be attached.) Whether individual or joint reports are used the following guidelines should apply.

Reports should be written in easily understood language, and be concise, consistent and not repetitious. Technical information may be added in an appendix.

Include in report:

- Reason for referral;
- When child seen and by whom;
- Assessment tools / process used;
- Outcome of assessments;
- Strengths and needs of child;
- Summary and recommendations;
- Appropriate review period.

The report should be written according to functional areas and should be goal and outcome focussed rather than discipline focussed.

The Assessment of Need process does not require a quantum of service to be specified.

The final report should be signed off by the team, or an individual on behalf of the team, listing all those involved with their discipline / title.

An example of a joint report template that might be useful is attached in Appendix 3.

Appendix 2 outlines the entire assessment process.

## Summary Report

The Summary Report is essential for the Assessment officer as it clearly captures the child's needs and the services required to address those needs. Assessors are asked to give their opinion as to whether the child has a disability or delay which is likely to last at least 12 months and which leads to the need for services.

If there are points of disagreement within the team regarding the child's needs, majority opinion should be recorded along with an outline of concerns raised. These can be noted on the Summary Report.

## **Review of the Assessment Report**

The Regulations accompanying the Disability Act state that the maximum period for a review of the Assessment Report to be carried out is 12 months from its completion or 12 months from the last review, but may be earlier if there is a significant change in health or education needs.

Please note that what is required is a review of the Assessment Report not a reassessment.

I. If a child is attending a service the review should be informed by the normal process of ongoing review of intervention. It is suggested that services should build the requirement for a review of the Assessment Report (AR) into their own review process, revisiting the AR to see if there should be any amendments when they conduct the child's service review. In most cases there should be no need for a separate process.

The clinicians who currently see the child should review the AR, not the original assessors if they are changed.

The Assessment officer (AO) will be in contact with the parents coming up to the review date to discuss any change in needs that they perceive. The AO will then write to the service provider asking them to review the AR, sending the original Summary Form and latest Service Statement. The service provider will be asked to amend the Summary Form as necessary and return it to the AO. Correspondence will be by

email where possible, so that service providers can amend the Summary Form using tracked changes and minimising paperwork.

Changes to the AR that may be identified at review time include:

- The child no longer meets the definition of disability under the Act
- A service not identified in the original AR is now required
- A service identified in the original AR is no longer required
- There is a requirement for an additional assessment to identify health needs
- There is a requirement for an assessment of educational needs (which the AO will refer to the local SENO)

Significant changes in circumstances should be discussed with the AO who will not normally attend review meetings with the team and parents, but may do so if seen as necessary.

- 1. Where a child is being seen by individual clinicians rather than a team, they also should build review of the AR into their normal practice of regular review, with collaboration with other clinicians where appropriate by telephone, email or teleconference.
- 2. If a child is on the service waiting list it is likely that the review will require some degree of reassessment to see if his or her needs remain the same or not.
- 3. If a child is not receiving services and is not likely to in the next 12 months, the AO will discuss with the parents whether new assessments are warranted at this time, given that if a service does become available new assessments will most likely then be conducted.

# Section 2: Interpretation Of The Terms Used In The Definition Of Disability

### Introduction

This document forms a part of the overall guidance to assessors and is designed to assist clinicians who have been asked to carry out assessments under the Disability Act 2005. As with all legislation, the precise wording employed must be studied carefully when interpreting the meaning of the Act. While the Act is clear that it is the Assessment officer who is asked to make a determination as to whether or not an applicant meets the definition of disability contained in the Act, they would normally do so having received advice from clinicians. Consequently, it is important that assessors have as clear and consistent an interpretation of the terms used in the definition as can be achieved.

It is important to emphasise that the definition of disability under the Act has not been considered judicially. These guidelines do not constitute a standard of practice and they are not intended to substitute for sound clinical judgment which is a matter for relevant professionals. This document can only suggest how the terms might be interpreted. It is not intended to be prescriptive.

#### The Definition of Disability Contained in the Disability Act 2005

The following are extracts from the Disability Act 2005. Section 2 provides the fundamental definition of disability while section 7 (2) expands on the term, "substantial restriction" used in section 2.

Section 2: "Disability", in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.

Section 7 (2): In the definition of "disability" in Section 2, "substantial restriction" shall be construed for the purposes of this Part as meaning a restriction which:

- a) is permanent or likely to be permanent, results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes, and
- b) gives rise to the need for services to be provided continually to the person whether or not a child or, if the person is a child, to the need for services to be provided early in life to ameliorate the disability.

### Important Aspects of the Definition

It is particularly important to note that the term "substantial restriction" refers to a restriction in a person's capacity to participate. It does not refer to the impairment. This is important as it is this restriction in capacity to participate that must be "permanent or likely to be permanent" according to the definition in the Act.

Furthermore, when the definition refers to the substantial restriction resulting in significant difficulty, it is referring to significant difficulty in one of the four areas of functioning listed:

- Significant difficulty in communication;
- Significant difficulty in learning;
- Significant difficulty in mobility;
- Significantly disordered cognitive processes.

It is important to emphasise that the Act focuses on difficulties in particular areas of functioning. It is also important to emphasise that the definition of disability contained in the Act does not make any reference to a diagnosis. Consequently, assessors are not asked to provide a diagnosis.

The Assessment officer is required to make a determination as to whether or not an applicant has a disability within the terms of the Act. The Assessment officer does this based on the information received from a variety of sources. Those carrying out the actual assessments are asked to provide their clinical opinion in relation to certain questions, given the information available to them.

Finally, an important characteristic of the definition is that **all the criteria must be met**. Careful attention must be paid to the Act's use of the words, "and" and "or".

#### **Interpretation of Terms and Phrases**

The following table highlights the various terms of importance. The terms in capitals in the left-hand column require definition and interpretation.

physical, sensory, intellectual o	r mental health
IMPAIRMENT	which is
ENDURING	and which results in a
SUBSTANTIAL RESTRICTION	in a person's
CAPACITY TO PARTICIPATE	in social or cultural life and which is
PERMANENT	or
LIKELY TO BE PERMANENT	and which, in turn, results in
SIGNIFICANT DIFFICULTY	in communication, learning or mobility or in
SIGNIFICANTLY DISORDERED	cognitive processes
AND	which gives rise to the
NEED FOR SERVICES	to be

According to the Act, for a person to be defined as having a disability, there must be a physical, sensory, intellectual or mental health...

PROVIDED CONTINUALLY	or, if the person is a child, to the need for services early in life to
AMELIORATE	the restriction in the capacity to participate.

Suggestions as to how some of these might be interpreted, have appeared either in the standard documentation developed during the implementation of the Act, or elsewhere.

Thus, the World Health Organisation defines "impairment" as a problem in body function or structure. "Enduring" has been taken internationally to mean lasting for 12 months or more. Guidance issued by the HSE states that the term, "continually" used in respect of the provision of services, may also encompass the situation in which services are provided intermittently or in response to conditions of an episodic nature.

For the assessing clinician, the terms that are likely to give rise to the most debate are, "permanent or likely to be permanent", "significant difficulty" and "substantial restriction" used in respect of a person's capacity to participate in social or cultural life in the State.

The table on the following pages provides some guidelines for clinicians who are requested to carry out an assessment under the Disability Act. The Assessment officer is legally obliged to make a determination as to whether or not an applicant meets the definition of disability contained in the Act but would normally do so only following clinical input.

Assessors are asked to complete a section of the **Summary Report** entitled, **"Determination of Disability – Supporting Information".** It is in this section that they are required to provide the answers to the questions that assist the Assessment officer in making his or her determination. If the Assessment officer relies solely on the answers provided by assessors, (bearing in mind what has already been stated above concerning how the Act demands that all criteria must be met), the answer to question 3 would have to be "yes" for the applicant to be deemed to meet the definition of disability.

### **Guiding Principles**

Before moving on to provide more specific suggestions on the interpretation of the terms used in the definition illustrated with examples, the following are some overall guiding principles:

- 1. Those carrying out the assessments must be suitably qualified, experienced and competent.
- 2. The issue of whether or not a child is experiencing, or may potentially experience, a substantial restriction in their capacity to participate must be judged on an individual basis.

- 3. Children should be compared with their normative peers.
- 4. Standardised assessment tools can be used if they are appropriate at the time. The results of these assessments may indicate deviations from the norm which are considered significant. This will be suggested in the guidance manuals for the standardised tests.
- 5. Clinicians are asked to decide whether or not a child is experiencing a significant difficulty in an area of functioning which falls within their area of competence.
- 6. Majority consensus among team members, on a child's level of needs, should be used in situations where there is a difference of opinion on the significance of difficulties.
- 7. Diagnosis alone does not indicate level of need but will be a factor for consideration. However, the Disability Act does not necessarily require a diagnosis to be made.
- 8. If a child requires frequent and/or ongoing physical assistance and/or supervision on a one-to-one basis in order to achieve reasonable outcomes they might be described as experiencing a significant difficulty. Where supervision is necessary at a distance or in a group, this may be taken to indicate that the difficulty is not significant. Requiring one-to-one attention may be regarded as an indication of a significant difficulty.

Term	Guidance On Interpretation

Impairment	Impairment may be defined as being a problem in body function or structure.
Enduring	Enduring may be interpreted as meaning that the condition is likely to last for 12 months or more.
Substantial Restriction In Capacity To Participate	The Act refers to a "substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State". Since the Act has only been implemented for children under five, this could be interpreted as referring to participation in age-appropriate activities or the potential to participate later in life.
	The following are examples of where an impairment may be deemed to result in a substantial restriction to participate:
	Alterations needed to child's physical living environment;
	Assistive technologies required;
	• Personal assistance (not normally required by a child of the same age) required in order for the child to carry out activities of daily living and participate fully in age appropriate activities;
	• There is an inability to communicate needs in everyday environments;
	• The child has considerable difficulty engaging in educational activities at the level of his/her peers;
	• The child is limited in ability to integrate socially, including participation in age-appropriate play;
	• Presence of emotional distress in relation to communication and/or feeding difficulty.
	<b>Note:</b> It is important to ensure that the child in question is being assessed in relation to the norms for any other child of their age and not in relation to the norms applying to the children normally seen by the assessing service.

Permanent Or Likely To Be Permanent	It is recognised that this part of the Act poses particular difficulties for assessors (especially in the case of young children) and necessarily involves a degree of judgement. Many clinicians have expressed a reluctance to label a child at such an early age and to commit such an opinion to paper. We have already stated that "enduring" might be taken to mean lasting I2 months or more. The term "permanent or likely to be permanent" could be interpreted in a similar way. The form provides space for the assessor to qualify his or her answer. It should be remembered that the Assessment Report resulting from the assessments arranged <b>must be reviewed at least within I2 months</b> . Therefore, any opinion given in the first instance can be revised as necessary.	
Significant Difficulty	The most important aspect of this section is that it refers to a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes. (Difficulty in one area only is sufficient). I.e. A significant difficulty in an area of functioning, not a significant difficulty as defined by a particular area of clinical expertise and not as defined by the existence of a large number of relatively minor difficulties. The ideal situation is for assessments not to be carried out in isolation from each other. Once again, a staged approach to answering this question may prove useful:	
	<ol> <li>Where a diagnosis has already been made, it may be obvious that there are significant difficulties in particular areas of functioning. Similarly, the presentation may make this obvious.</li> </ol>	
	2. Informal assessment techniques and co-operation with other assessors may provide sufficient information to reach a decision.	
	3. The following are examples of what might be regarded as being significant difficulties in each of the areas of functioning referred to in the Act:	
	Communication	
	• Disordered rather than delayed pattern of communication.	
	• A 4½ - 5 year old child more than 15 months behind chronological age in two or more areas on informal assessment. Or, proportionately according to age.	

<ul> <li>Inability to access environment communicatively to meet needs.</li> </ul>
<ul> <li>The child would often not be understood by people outside the family.</li> </ul>
<ul> <li>Inability to demonstrate attention and listening attention for formal assessment.</li> </ul>
<ul> <li>Problems in developing and using non-verbal communication skills.</li> </ul>
<ul> <li>Restriction in vision which significantly impacts on communication.</li> </ul>
<ul> <li>Restriction in hearing which significantly impacts on communication.</li> </ul>
Learning
• In multi-domain assessment, there is significant delay in two or more areas of development. I.e.
motor;
communication;
cognition (problem solving);
sensory;
adaptive and personal-social skills (affective, behavioural and interactive patterns).
<ul> <li>Cognitive functioning on standardised assessment is at 2 SD or more below the mean.</li> </ul>
<ul> <li>Significant delay / disorder in performance tasks. E.g.</li> </ul>
visuo-spatial awareness;
speed of performance and precision.
<ul> <li>Adaptive functioning is significantly delayed or impaired, including:</li> </ul>
levels of independence;
daily living / self-care skills.
<ul> <li>There are significant delays or impairments in social skills development which are affecting socialisation and learning. I.e.</li> </ul>
how the child interacts with family;
Peers, strangers.

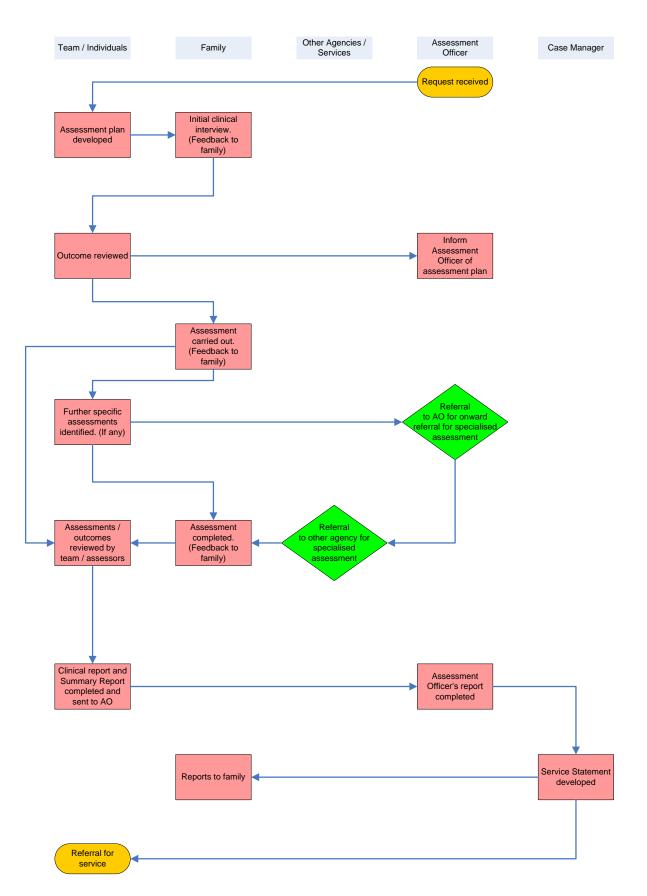
<ul> <li>Significant delays in the development of play skills.</li> <li>Impact of delay on family functioning is high, including access to activities of daily living. This may be associated with severe emotional and/or behavioural difficulty / disorder / disturbance including:</li> </ul>	
	1
	2
injurious behaviour to self or others;	
severe withdrawal - emotional withdrawal or inhibited pattern - doesn't seek comfort in distress, reduced social and emotional reciprocity;	
tantrums (high in frequency and duration) 3+hrs a day - excessive levels of irritability, disturbed intensity of emotional expression.	
<ul> <li>Patterns of behaviour and levels of functioning observed occur across different contexts / settings / relationships.</li> </ul>	
Mobility	
• The child has a condition, (e.g. respiratory, cardiac, musculoskeletal, neurological, sensory or surgic that affects endurance / ability to participate in skills such as walking, negotiating steps / stairs / playgrour equipment etc to such an extent that they require assistance / supports.	'
Child whose overall functional performance is impacted significantly as evidenced in results of tandardised assessment tests. For example: Movement ABC, Peabody, Brunicks. (These are examples only. It is not a prescriptive list. Scores / levels / deviations in specific range of assessment tests which lemonstrate significant difficulties to be agreed by clinicians).	
<ul> <li>Child unable to organise movements / negotiate environment on daily basis without high risk of inju or need for ongoing guidance / assistance.</li> </ul>	ry
Significantly Disordered Cognitive Processes	
Disturbed affect and pattern of behaviour:	
difficulty with regulation of affects including depressed mood, anxiety, fear, anger;	
need to consider if pattern of emotional expression is generalised across settings and relationships.	
• Symptoms are pervasive and impair functioning. E.g. Participation in age appropriate activities.	

• Difficulty processing sensory input suggested by unusual and extreme responses to normal sensory stimuli in the environment.
• Combination of difficulties with communication, learning, mobility and disordered cognitive processes which indicate need for assistance in daily activities.

#### Appendix I - Criteria for Selection of Assessment Tools

- I. Is the purpose of the assessment tool clearly stated?
- 2. Is it considered good practice / what evidence supports its use?
- 3. Who can administer and interpret the test?
- 4. Are results quantifiable can they be measured?
- 5. Are there any comparison tools that can be used with it?
- 6. Are there other tools, not currently in my possession, which would be more appropriate to use?
- 7. Have I the necessary training and experience to use the tool?





## Appendix 3 – Sample Joint Report Template

Clinical Report	
Name:	
Address:	
D.O.B:	Chronological Age:
Date of Assessment:	Date of Report:
Referred by:	
Reason for Referral:	
Other Agencies Involved:	
Pre-school / School:	
Assessment Tools Used:	
Developmental History:	
Presentation:	
Social – Emotional – Behaviour:	
Communication and Language:	
Cognitive Development:	
Gross Motor Development:	

Fine Motor Development:
Sensory Motor Observations:
Strengths:
Needs:
Conclusions:
Recommendations:
Date for Review:
Signed on Behalf of the Team:
Print Name and Qualifications:
Team Members Carrying Out Assessment (with discipline and title):



# Disability Act 2005 Assessment Officer: Process And Practice Guidelines, I 2<sup>th</sup> June 2009

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## Introduction.

This document has been drawn up by the Assessment officer Reference Group and approved by the Project Team for the Implementation of the Disability Act. It is designed to act as a guide to Assessment officers in the fulfilment of their role. It is also hoped that it will be of assistance to others involved in the assessment process such as General Managers, Disability Managers, Service Managers and health professionals involved in carrying out assessments under the provisions of the Disability Act.

The document has been divided into five main sections covering the five major phases of the Assessment officer's role:

- Application;
- Stage I Desk-top assessment;
- Stage 2 Professional assessments;
- The return of professional assessments;
- Issuing the Assessment Report;
- The Redress System.

The document should be read in conjunction with the similar document produced by the Case Manager Reference Group which guides the Liaison Officers in the fulfilment of their role, **Liaison Officer – Process and Practice Guidelines** (28<sup>th</sup> July 2008).

## I. Application Received.

#### I.I. Checking the Application

**1.1.1** When an application for an assessment of need under the Disability Act 2005, (referred to in this document as "the Act"), is received in an LHO, it should be opened, date-stamped and checked for:

- Eligibility in respect of age;
- Appropriateness;
- Completeness;
- The existence of an Assessment Report for which the review date has not expired or of an active application in the assessment of need process. The latter would not be treated as a new application although a review may be required.

**1.1.2** If the Assessment officer is not in the office, arrangements should be made for this procedure to be carried out on his/her behalf. This arrangement is in addition to any Assessment officer cross-cover arrangements made between LHOs.

**1.1.3** If the Assessment officer is of the opinion that intervention is required as a matter of urgency, the Assessment officer should ensure that a referral is arranged to the relevant service provider. In any event, the Assessment officer should ensure that the assessment process does not unduly hinder or delay intervention.

**1.1.4** In accordance with the Disability (Assessment of Needs, Service Statements and Redress) Regulations 2007 the Assessment officer will process applications for assessment in order of the date on which they are received. Where two or more applications are received on the same date then they shall be processed in alphabetical order of the surname of the applicant.

- Ref. Application Form.
- Ref. Guidance for Assessors.

#### I.2. Eligibility in Respect of Age

**1.2.1** When determining eligibility in respect of age, Guidance Note No. I should be followed.

- Ref. Guidance Note No. I. Age. Amended by the Interpretation of Age-Limit September 2008.
- Ref. Disability Act 2005 (Commencement) Order 2007.S.I. No. 234 of 2007.

#### **I.3.** Appropriateness of Applications.

**1.3.1** "Appropriateness" refers to issues such as:

• Is the application made by a person authorised to do so under section 9 (2)?

• Is the applicant applying to the correct LHO? The correct LHO is the one in which the child lives.

**1.3.2** Section 9 (2) (d) of the Act allows for application to be made by an advocate appointed by the Citizen's Information Board (CIB). (Formerly Comhairle). The CIB has yet to establish this service.

**1.3.3** Section 9 (4) of the Act states that an employee of the HSE "may arrange for an application....to be made by or on behalf of the person". In practice, the employee will suggest to the person that they make an application and the actual application and the relevant consents are submitted by the person.

**1.3.4** Where a child is in the care of the HSE, the Assessment officer should seek advice on consent issues from the relevant Social Worker.

**1.3.5** Where it is clear that the application is not appropriate, one of the following actions should be taken:

- If the application has not been made by an appropriate person authorised under section 9 (2), the person making the application should be contacted immediately and guidance given on how an appropriate application might be made;
- If the application has not been made to the correct LHO, the application should be referred on to the appropriate LHO immediately and the applicant notified. The relevant Assessment officer should also be notified by e-mail.

**1.3.6** In any event, the Assessment officer should ensure that appropriate referrals are made to other health services and that this is not left up to the applicant to pursue.

#### I.4. Completion of Applications

**I.4.1** If the application form is not complete, a letter requesting the missing information should be sent out within five working days.

**1.4.2** When all information is received the application should be recorded as complete, along with the date, in the "For Office Use Only" section of the application form.

**1.4.3** All complete applications should be recorded on the IT system regardless of whether or not they are deemed appropriate.

• Ref. Standard Letter. Further Application Information.

#### I.5. Existing Assessment Report

**1.5.1** It may become evident that an assessment has already been carried out under the Act and the specified review period has not yet expired. In such circumstances, the HSE may decline an application for an assessment of need.

#### I.6. Consent Issues

**1.6.1** An application may be accepted with a signature from one of two parents or guardians. The additional consent of the second parent or guardian should only be sought when it becomes clear that there may be uncertainty as to whether or not the second parent or guardian would provide consent if asked. Such instances will be dealt with on a case-by-case basis.

**1.6.2** Some general principles apply to the issues of data-protection and consent:

- The individual concerned must understand what information is being collected and/or shared. It is an important part of the Assessment officer's role to explain the complete process to the applicant and to provide them with information to which they may later refer;
- The information may only be used for the purpose for which consent was provided. In this case, for the purpose of assessment or service provision. Information legitimately held by the HSE may be circulated within the HSE for these purposes. This also applies to HSE funded agencies where they are involved in assessment or service provision;
- A general, "need-to-know" principle applies. This means that only those who require the information should receive it and that they should receive only the information they require;
- In particular, child protection reports would not normally be sought or circulated. If such a report is relevant at all, it is sufficient that potential assessors are aware that a family is in touch with HSE Social Services.
  - Ref. Memo on Consent Dated 12.12.08.

#### I.7. Application Acknowledged.

**1.7.1** A letter of acknowledgement must be sent out within 14 days of receipt of a completed application form. This time-frame is stipulated in the Regulations accompanying the Act.

**1.7.2** The date of receipt of the completed application form is the date on which the first period of three months (within which the assessment must commence), referred to in section 9 (5) of the Act, commences. "...the **Executive shall cause an assessment of the applicant to be commenced within 3 months of the date of the receipt of the application...**" (See also paragraph 3.1.2. below).

**1.7.3** A file should be opened when the application is acknowledged.

• Ref. Standard Letter. Acknowledgement.

- Ref. Disability (Assessment of Need, Service Statements and Redress) Regulations. S.I. No. 263 of 2007.
- Ref. Standard Letter. Ineligible-Existing Report.
- Ref. Filing System Contents.

## 2. Desktop Examination of the Application. Stage 1.

#### 2.1. Evidence of Disability

**2.1.1** If it is clear that the person does not meet the definition of disability, Guidance Note No. 24(a) should be followed.

2.1.2 In cases where uncertainty remains, clinical advice should be sought.

**2.1.3** If uncertainty still remains having sought clinical advice, the child should be referred for assessment under the Act.

**2.1.4** In order to facilitate forward planning, those likely to be involved in the assessment process may be e-mailed early in the process. It should be made clear that no action is required from them at this stage.

• Appendix. Guidance Note No. 24(a). Treatment of those not meeting the Definition of Disability.

#### 2.2. Ineligibility

**2.2.1** If, having checked for appropriateness, eligibility in respect of age and completeness, and having acknowledged receipt of the completed application form, it subsequently becomes evident that an Assessment Report is in existence for which the review period has not expired, the relevant standard letter should be sent. NB. The existence of an active application in the assessment of need process would not be treated as a new application although a review may be required. (See paragraph 1.1.1.).

**2.2.2** Where a child is deemed ineligible for an assessment under the Act, parents or guardians should be informed that their right to apply to the HSE for services is not affected by the fact that they do not qualify for an assessment under the Act.

#### 2.3. Onward Referral

**2.3.1** Reports accompanying the application may indicate the need for a referral to the NCSE under section 8 (3) or to another public body. Such an indication may become apparent at various stages of the process and referral should be made at the earliest possible opportunity.

**2.3.2** Where a referral to the NCSE is indicated, the Guidance Note concerning referral for assessment of educational needs should be followed.

**2.3.3** Where a referral to a housing authority is indicated, the protocols for such referrals drawn up by the DoHC should be followed.

**2.3.4** In either case, the applicant should be contacted and made aware of the Assessment officer's intentions.

**2.3.5** The Assessment officer should check that the applicant has provided the appropriate consent.

**2.3.6** When referring on to a body outside the HSE, the Assessment officer should be mindful of the general principles applying to matters of consent noted in paragraph 1.6.

- Ref. Guidance Note on. Referral for Assessment of Educational Needs.
- Ref. Protocols for Referral to another Public Body.

#### 2.4. Contacting Parents or Guardians.

**2.4.1** Parents or guardians should be contacted in order to:

- Clarify why they think the child needs an assessment;
- Gather further relevant information which may be of benefit in identifying the child's health and education needs
- Explore their expectations of the assessment of need process.

**2.4.2** Contact with parents or guardians is important at all stages on the process so that they are kept informed of developments and queries can be dealt with as they arise.

**2.4.3** The form of contact is at the discretion of the Assessment officer and should be informed by reference to the criteria for deciding the type of contact with parents.

**2.4.4** Cognisance should also be taken of the Lone Worker Policy.

**2.4.5** If the interview is to be by phone, a preliminary call should be made to agree a time and to provide an estimate of the potential duration.

**2.4.6** The Additional Information About Your Child Form (also known as Application Form-Part 2) should be used <u>consistently</u> to guide the interview with the parents. This form, and any other information gathered from contact with parents or guardians, should be made available to potential assessors in order to minimise the overlap between Assessment officer and assessor contact with parents or guardians.

In cases where parents or guardians fail to agree an interview time or an appointment is missed, the following procedure should be followed:

• Check the reasons for non-attendance with the family. (In particular, be aware of literacy or language issues.);

- Attempt to negotiate a new appointment;
- Enlist the assistance of service providers already involved;
- If a third appointment is missed, a letter is issued informing the parent that their file has been closed and that they may re-apply in the future. The file is also closed on IT system.

**2.4.7 NB:** An important function of the early contact with parents of applicants is to ensure that the whole process from the time of application through to the provision of services and future review of Assessment Reports is explained in detail. This explanation should include:

- Reference to the standards applying to the assessment of need process;
- An explanation of the roles of those involved in the process;
- An explanation of the independence of function afforded to the Assessment officer by the Act;
- An explanation of "informed consent" and its application in this case;
- Clarification of the important differences between the process governing the assessment of need and that governing the provision of the Service Statement;
- In particular, the fact that assessments are carried out without regard to resources or capacity to deliver while Service Statements provide the detail of which services are going to be provided, given current resources;
- Reference to the redress system;
- Provision of the explanatory leaflet.

**2.4.8** In addition to the above, the Assessment officer should take the opportunity to explore the expectations that parents or guardians have of the process with particular emphasis on the following:

- The assessments may well be carried out by the service provider in which a child is receiving intervention and the process is not designed to provide a second opinion;
- Assessing a child's health needs does not necessarily involve a diagnostic assessment;
- The process will not necessarily result in a higher level of service provision than that which is already in place.

**2.4.9** Where specific assessments are requested by parents, the Assessment officer should ascertain the reasons for the request and ensure that the request is based on a presenting need. It should also be clarified with parents, that the decision as to whether or not a particular assessment is clinically appropriate lies with the clinician at whom the request is directed.

**2.4.10** Where the Assessment officer receives an application in respect of a newly diagnosed baby, it may be appropriate to introduce the family to the service required, (or arrange for that to happen), rather than process the

application at that time. This would provide the family with the opportunity to gradually build up a relationship with the service and the Therapists involved and to acclimatise themselves to their new situation. In such circumstances, the child's application can be put on hold for a period of time, with the agreement of the parents or guardians.

- Ref. Standard Letter. Client Interview.
- Ref. Criteria for Deciding Type of Parental Contact.
- Ref. Lone Worker Policy.
- Ref. Additional Information Form.
- Ref. HIQA Standards for the Assessment of Need.
- Ref. Guidance Note No. 25. Independence of Assessment officers.
- Ref. Explanatory Leaflet.

#### 2.5. Accessing Existing Reports.

**2.5.1** Using the information gleaned from the application form and the initial contact with parents or guardians, the Assessment officer should contact the relevant professionals to ask them to forward copies of existing, relevant reports. A standard letter is provided on the IT system for this purpose. Existing reports form an important part of the overall information available to potential future assessors and to the Assessment officer. Consequently, the Assessment officer should seek relevant existing reports at the earliest possible opportunity.

**2.5.2** Assessment officers should be selective in seeking existing reports and should be clear that each will fulfil a necessary function. Reasons for obtaining an existing report are as follows:

- It is necessary in order to provide the Assessment officer with sufficient evidence to warrant further assessment;
- It is necessary to gain the information required to ascertain the health and education needs without requiring further assessments;
- It is required by potential assessors in order to enable them to carry out their own assessments.

Please note that it may be sufficient for potential assessors to know that a report exists so that they can access it themselves if they deem it necessary.

**2.5.3** It would normally be sufficient to obtain the most recent reports from current service providers.

**2.5.4** Guidance has been issued concerning the criteria to be applied when deciding whether or not existing reports can be accepted as a part of the assessment of need process.

• Ref. Standard Letter. Request for Reports.

• Ref. Guidance Note No. 11. Previous Reports.

#### 2.6. Following Contact with Parent(s) or Guardian(s).

**2.6.1** If, following the interview with the parents or guardians, it is clear that there is evidence that the child may not meet the definition of disability, the process outlined in paragraph 2.1. should be followed.

**2.6.2** If, following the interview, the need for a referral to the NCSE under section 8(3) or to another public body is indicated, the process outlined in paragraph 2.3. should be followed.

#### 2.7. Arranging Assessments.

**2.7.1** Before making arrangements for clinical assessments to be carried out, Assessment officers should be satisfied that there is sufficient evidence to suggest that the child may meet the definition of disability. In those cases where they are not satisfied, they should afford the parents an opportunity to provide that evidence.

**2.7.2** It is the Assessment officer's role to arrange for assessments to be carried out. Decisions in this regard are based on information from the following sources:

- The Application Form;
- The interview with parents or guardians;
- Existing reports received;
- Clinical advice. This should be sought if deemed necessary.

**2.7.3** The Assessment officer should ensure that they request assessments based on presenting needs rather than broadly requesting assessments from certain disciplines. If the Assessment officer is unsure of the need for a particular assessment, s/he should contact the relevant assessor or other relevant clinician and discuss the matter. Guidance has been developed to assist Assessment officers in deciding which assessments should be requested.

**2.7.4** Assessment officers should be familiar with the documents, Guidance for Assessors and Guidance on Requesting Assessments.

**2.7.5** Assessment officers may be in the position of arranging for assessments to be carried out either by a range of individual clinicians or by a team. When referring to a team for assessment, it is unnecessary, in most circumstances, to request individual assessments from certain clinicians. It is sufficient to request an assessment of health needs occasioned by the disability.

• Where an assessment is requested of a team and the team is unable to carry it out as requested, they will inform the Assessment officer in writing of the clinical reasons for this and will confirm in writing that the decision was not based on resource considerations.

**2.7.6** Assessment officers should use the forum provided by the Local Implementation Group (LIG) to ensure that good lines of communication are established with potential assessors and that the legislative obligations on Assessment officers and others involved in the process are understood.

**2.7.7** A standard letter is sent to each potential assessor. This should include:

- A copy of the Application Form;
- A copy of the Additional Information Sheet;
- Reference to or copies of any relevant, previous reports;
- The HIQA Standards for the Assessment of Need. (Sent once and referred to thereafter);
- The Guidance for Assessors including the section on Interpreting the Definition of Disability Contained in the Act. (Sent once and referred to thereafter);
- A Summary Report form;
- Any other useful information.

**2.7.8** All assessment requests should be logged on the IT system in order to facilitate tracking and targeting of issues arising.

**2.7.9** The letter to the assessor must include the latest possible date on which the assessment must be returned to the Assessment officer. The date for return will be at least two weeks before the Assessment Report is due to be sent to the Liaison Officer.

**2.7.10** If the time-frame is extended with the agreement of the parents / guardians, the date on which the Assessment Report is due, as entered on the IT system, must be changed by the Assessment officer.

**2.7.11** The legislation allows for the assessment to be commenced within three months of the date of receipt of the completed application and completed "without undue delay" which is defined in the Regulations as meaning, within a further three months. Given the fact that non-adherence to the time lines is one of the potential grounds for complaint, it is essential that the beginning and end of each stage is clearly marked. The start of this second stage of the assessment process is defined by the date on the letter sent by the Assessment officer arranging the first professional assessment.

**2.7.12** Assessment officers and potential assessors are expected to maintain contact in order to manage this process and ensure that assessors have adequate time to complete their assessments, that the assessments are completed within the time lines and that the process is completed without undue delay.

Ref. Guidance on Requesting Assessments.

- Ref. Standard Letter Request for Assessments.
- Ref. HIQA Standards for Assessment of Need.
- Ref. Guidance for Assessors.
- Ref. Summary Report form.

#### 2.8. Co-ordinating Assessments.

**2.8.1** The letter used when requesting assessments allows for other assessments requested to be noted so that assessors may be in communication with each other, co-ordinate their assessments and discuss their findings.

2.8.2 It is the Assessment officer's role to ensure that all assessors are:

- Informed of the names of all other assessors who have received requests to assess the child;
- Are aware of their obligations under the HIQA Standard No. 5 to carry out the assessments in a co-ordinated manner in order to accurately identify the needs of the child and to achieve a comprehensive report and to agree prioritisation of health needs.

**2.8.3** In particular, Assessment officers should be aware of the need to ensure co-ordination where further assessments are requested later in the process after initial letters requesting assessments have been sent.

**2.8.4** Assessors also have an obligation to ensure that they co-ordinate their assessments with those of other clinicians.

**2.8.5** Prior to sending out assessment requests, The Assessment officer should try to ascertain who is carrying them out in order to include contact details in the letter.

#### 2.9. Assessor Qualifications

**2.9.1** It is the Assessment officer's role to ensure that potential assessors are suitably qualified, aware of the Guidance for Assessors and aware of the HIQA Standards for the Assessment of Need.

**2.9.2** If assessment requests are channelled through a central administrator, the Assessment officer needs to make arrangements to ensure that they know the identity of the person carrying out the assessment.

**2.9.3** In order to ensure that those requested to carry out assessments are suitably qualified and experienced, Assessment officers should request, on an annual basis, a letter from the employers of assessors stating that those who will be carrying out assessments under the Act in the coming year will be so qualified and experienced. In the case of assessors employed by the HSE, this letter should be signed by the General Manager. In the case of assessors employed in voluntary sector agencies, the letter may issue from the organisation's central office. (Assessors are also asked to state their qualification when completing the Summary Report form.)

#### 2.10. Where an Assessor is Unable to Carry out an Assessment.

**2.10.1** If an assessor is unable to carry out an assessment, the Assessment officer should be notified in writing and reasons provided.

#### 2.10.2 Valid reasons may include the following:

- A material mistake of fact is identified during an assessment. E.g. clinical content of a report has been misinterpreted;
- The specific assessment requested by the parents or guardians is not age appropriate and/or not required;
- The applicant/family has missed a number of appointments and/or is not engaging with an assessor. (See paragraph 3.2.3.).

**2.10.3** Other issues may arise which may delay an assessment. These should be notified to the Assessment officer at the earliest opportunity.

**2.10.4** If an assessor determines that an assessment which has been requested should not take place, they should explain their reasons to the Assessment officer in writing. This letter should also confirm that the decision was not based on resource considerations.

**2.10.5** Invalid reasons for being unable to carry out an assessment may include the following:

- There is a waiting list for assessments;
- Staff shortages due to leave or non-recruitment;

**2.10.6** In the event of an assessment not being obtainable from the normal assessors, Assessment officers should discuss the issue with their General Manager. Solutions might include:

- GM requesting the service manager to complete the assessment;
- A different agency;
- A neighbouring LHO Area;
- A private clinician.

**2.10.7** In the event of an assessment being requested from a private assessor, Guidance Notes No. 15 and 16 should be followed.

- Ref. Guidance Note No. 15. Private Assessors.
- Ref. Guidance Note No 16. Private Assessors Agreement.

## 3. Assessment Stage – Stage 2

#### 3.1. When Stage 2 Commences and Finishes.

#### 3.1.1

**3.1.2** According to section 9 (5) of the Act: "...the Executive shall cause an assessment of 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".

**3.1.3** The term, "the assessment of the applicant" is taken to refer to the professional assessments. I.e. The Assessment Stage – Stage 2.

**3.1.4** In order to vindicate the applicant's rights under the Act and to measure performance within the system, it is necessary to define the exact time that this stage commences.

**3.1.5** The commencement of stage 2 is taken to be as detailed in paragraph 2.7.11. i.e: The start of this second stage of the assessment process is defined by the date on the letter sent by the Assessment officer arranging the first professional assessment.

**3.1.6** Assessment officers and potential assessors are expected to maintain contact in order to manage this process and ensure that assessors have adequate time to complete their assessments, that the assessments are completed within the time lines and that the process is completed without undue delay.

**3.1.7** According to paragraph 10 of the Regulations: "The Executive shall complete the assessment and forward the assessment report to the Liaison Officer within a further three months from the date on which the assessment commenced..." In other words, the term, "without undue delay" in section 9 (5) of the Act is interpreted to mean within a further three month period.

**3.1.8** The date on the e-mail sent from the Assessment officer to the Liaison Officer attaching the Assessment Report, is taken to be the date on which stage 2 finishes and the one-month period within which the Service Statement should be produced, begins.

• Ref. Guidance Note No 18. Issuing the Assessment Report and the Service Statement at the same time.

#### 3.2. Inability to Comply with the Time-Frame.

**3.2.1** If an assessor is unable to comply with the time-frame, s/he should notify the Assessment officer in writing as soon as possible stating the reason.

**3.2.2** Paragraph 10 of S.I. 263 of 2007 (which refers to "exceptional circumstances" in which an assessment may be delayed), may be invoked where

there are clinical reasons for the delay or pressing family issues affecting the applicant.

**3.2.3** Where an assessment is delayed because the applicant was unable to attend an appointment, the process may be put on hold pending resolution of the issues. The following procedure should be followed:

- The particular service concerned may have a policy for handling non-attendance. In such a case, this policy should be implemented.
- In the absence of a particular policy relating to the service, the assessor should:
  - Check the reasons for non-attendance with the family. (In particular, be aware of literacy or language issues.);
  - Attempt to negotiate a new appointment;
  - Enlist the assistance of other service providers already involved;
- If a third appointment is missed, the Assessment officer should be informed. The Assessment officer will then issue a letter informing the parents that the file has been closed and that they may re-apply in the future. The file is also closed on IT system.

#### 3.3. Assessments Identified Late in the Process.

**3.3.1** Where an assessor identifies the need for an assessment late in the process, the relevant Guidance Note should be followed.

• Ref. Guidance Note on Assessments Identified During the Process – To be issued.

## 4. Assessments Returned.

#### 4.1. Summary Report Form Returned Incomplete

**4.1.1** The Assessment officer requires all assessment documentation (Professional Report and Summary Report including the Determination of Disability – Supporting Information section), to be returned complete. However, ensuring that the child concerned receives intervention as soon as possible is the paramount consideration.

**4.1.2** The Guidance for Assessors document has been developed to assist assessors in this regard. This document includes advice on interpreting the terms used in the definition of disability contained within the Act.

**4.1.3** It should be remembered that it is the Assessment officer who makes the determination as to whether or not a child meets the definition of disability contained in the Act. This is done, taking into account, the information provided by clinicians and others.

**4.1.4** The Assessment officer requires all clinicians involved in the assessment to return the Summary Report. However, the s/he may make a determination based on information contained in a form returned by one clinician.

**4.1.5** Further, the Assessment officer may make a determination without information contained in the Determination of Disability – Supporting Information section, if s/he is of the opinion that there is sufficient other information upon which to base such a decision.

**4.1.6** The information contained in sections 7 and 8 of the Summary Report is required to populate sections 6 and 7 of the Assessment Report.

**4.1.7** The content of the Assessment Report is stipulated in the Act and Assessment officers require the assistance of clinicians to ensure that the HSE meets its statutory obligations.

**4.1.8** Local Implementation Group meetings and/or other forums should be used to explain the necessity of this information to assessors. If it were not received, the Assessment officer would be placed in the position of having to interpret the professional reports of the clinicians involved.

**4.1.9** The assistance of the General Manager and the Disability Manager should be sought in dealing with these issues.

• Ref. Guidance for Assessors.

#### 4.2. The Assessor has not completed / returned a full report.

**4.2.1** Where an Assessment officer has requested a clinician to carry out an assessment under the Act, a full report is not returned and none of the reasons listed in paragraph 2.10.2. apply, the Assessment officer is not in a position to fulfil his/her obligations under the Act.

**4.2.2** In these circumstances, the Assessment officer should contact the assessor concerned by e-mail or letter. This communication should explain the legislative position and request the reasons for not returning the report in writing.

**4.2.3** The assistance of the General Manager or Disability Manager may be required to resolve the situation.

## 5. Issuing the Assessment Report

# 5.1. Where the Determination is that the Child does not have a Disability

**5.1.1** In those cases where the information received leads the Assessment officer to determine that the child does not have a disability as defined in the Act, Guidance Note No. 24(a) should be followed.

**5.1.2** This leads to the issuing, directly to the person concerned, an Assessment Report noting that the Assessment officer has determined that the person does not meet the definition of disability contained in the Act.

**5.1.3** The Assessment officer should ensure that the person is referred on to any necessary health services as appropriate. It should be made clear that, a determination that a person does not meet the definition of disability under the Act does not affect access to any health services deemed necessary.

**5.1.4** When the Assessment Report is complete, the Assessment officer should contact the parents with a view to clarifying the next steps in the process.

- Ref. Guidance Note No. 24(a) Treatment of those not meeting the Definition of Disability.
- Ref. Assessment Report No Disability.

#### 5.2. Where the Determination is that the Child has a Disability.

5.2.5 In those cases where the information received leads the Assessment officer to determine that the child has a disability as defined in the Act, the Assessment Report should be completed and sent to the Liaison Officer in accordance with Guidance Note No. 18 and the Liaison Officer – Process and Practice Guidelines.

5.2.6 When the Assessment Report is complete, the Assessment officer should contact the parents with a view to clarifying the next steps in the process.

- Ref. Assessment Report Disability.
- Ref. Guidance Note No. 18. Issuing the Assessment Report and Service Statement.
- Ref. Liaison Officer Process and Practice Guidelines.

## 6. Redress System.

#### 6.1. Protocols for Staff Handling Complaints and Appeals

**6.1.1** The Disability Act makes provision for a separate redress system. Separate protocols have been developed to guide staff in handling complaints and appeals in this regard. This issue is not dealt with in these guidelines.

#### 6.2. Grounds for Complaint.

**6.2.1** An applicant may make a complaint in relation to one or more of the following:

- a) a determination by the Assessment officer concerned that he or she does not have a disability;
- b) the fact, if it be the case, that the assessment under section 9 was not commenced within the time specified in section 9(5) or was not completed without undue delay;

- c) the fact, if it be the case, that the assessment under **section 9** was not conducted in a manner that conforms to the standards determined by a body referred to in **section 10**;
- d) the contents of the Service Statement provided to the applicant;
- e) the fact, if it be the case, that the Executive or the education service provider, as the case may be, failed to provide or to fully provide a service specified in the Service Statement.

**6.2.2** Any complaints that an applicant may have which do not fall into the categories mentioned above should be dealt with in accordance with the provisions of part 9 of the Health Act 2004.

#### 6.3. Redress System Structures

**6.3.1** Two dedicated Complaints Officers have been appointed and are based in the Consumer Affairs Division of the HSE. An independent Office of the Disability Appeals Officer has also been established.

- Ref. Redress Protocols
- Ref. Complaints leaflet

## Appendix 5 – National Council for Education circular

An Roinn Oideachais agus Scileanna Rannog Oideachais Speisialta Cor na Madadh Átha Luain Co. na hIarmhí Department of Education and Skills Special Education Section Cornamaddy Athlone Co. Westmeath

#### Circular No. 0020/2011 Circular to the Management Authorities of National Schools on the Assessment of Need process under the Disability Act 2005

#### I. Background

As outlined in Circular 51/2007, the provisions of Part 2 of the Disability Act, 2005 came into operation in relation to persons under 5 years of age on 1 June 2007. Under its provisions, parents may apply for an assessment of need under the Act if they are of the opinion that the child may have a disability in terms of the Act.

Disability under the Act is defined as follows:

"Disability", in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.

"Substantial restriction" is considered to mean a restriction which:

- a) is permanent or likely to be permanent, results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes, and
- b) gives rise to the need for services to be provided continually to the person whether or not a child or, if the person is a child, to the need for services to be provided early in life to ameliorate the disability.

#### 2. The Assessment of Need under the Disability Act

Assessment Officers are charged with organising the assessment of need for the HSE. The Assessment Officer must organise an assessment of the child within tight statutory time frames. The assessment focuses on the child's needs and may not necessarily result in a diagnosis which meets the DES criteria for resource allocation. It is the statutory duty of the Assessment Officer, taking cognisance of available clinical evidence, to make a determination as to whether or not a child meets the definition of disability contained in the Act. It is this decision which determines whether or not the child is entitled to the benefits of the Act's provisions.

#### 3. Education and the Disability Act

Under Section 8 (3) of the Disability Act, the Assessment Officer may request assistance from the NCSE in identifying the educational needs of the child. A process has been agreed for timely contact and response to the HSE by the NCSE to these requests.

The Assessment Officer (HSE) contacts the relevant SENO (NCSE) when an educational need is identified as part of the assessment process. The SENO informs the Assessment Officer of the education services which will be made available to the child. These services will be based on the relevant criteria applying at the time, with regard to provision for the education of pupils with special educational needs, including assessment and intervention and using the approach outlined in the NEPS Guidelines - A Continuum of Support - the General Allocation and resources allocated to schools by the NCSE, on the basis of criteria set out by the DES.

In order to ensure that parents have all the information and support they need, the contact details of the SENO will be made available to the Assessment Officer for parents' use, if required.

#### 4. The School and the Disability Act Process

# (i) What to do in terms of intervention prior to advising a parent about Assessment of Needs

Where a child under the age of 5 presents as having learning and or behavioural emotional or social difficulties in school, teachers should follow the approach to assessment and intervention outlined in the NEPS Continuum of Support Guidelines to address those needs in the first instance.

Applications for assessment of need under the Act should be made by the parent or guardian. In cases where a child under the age of 5 years appears to have a disability as set out above, and has not been assessed under the Act, the principal may inform the parents of the assessment of need process. Information leaflets for parents are available from HSE Local Health Offices, in GP clinics and HSE local health centres. Information is also available on the HSE website.

Principals should be aware that it is not appropriate for them to refer a child for assessment of need under the Disability Act. This process may only be initiated by a parent or guardian.

(ii) School Response to pupil need following an Assessment of Needs Where a child has been assessed as having a high incidence special need as set out in DES Circular 02/05, schools should support the child through the General Allocation Model for resource teaching.

As previously noted, assessment under the Disability Act focuses on a child's needs and does not necessarily result in a diagnosis which may be required to meet the DES criteria for low incidence special educational needs. In cases where it is evident from the reports supplied by the parent/s from the assessment of need process that the child meets the criteria for additional resources under the DES criteria for low incidence special need, the principal may make an application to the SENO in the normal way. As in all cases, the principal may consult with the SENO as to whether or not the child meets the required criteria.

Schools may use the information from assessment of need report/s provided to them by the parents to plan for differentiation and/or additional teaching support depending on the level of need of the child. The school may consult the NEPS psychologist when planning for a child with complex needs.

#### (iii) Communication

It has been agreed between the HSE, NCSE and NEPS that the appropriate line of communication for exchange of information under the Act is between the Assessment Officer and the SENO. It is, therefore, not appropriate for school principals to make direct contact with Assessment Officers or other HSE staff in this regard. Any queries regarding the assessment of need or intervention with a particular child should be directed to the local SENO.

This circular can be accessed on the Department's website <u>www.education.ie</u>

If you have any queries with regards to this circular please contact Special Education Section on 090 648 3747. Teresa Griffin, Principal Officer, Special Education Section

## **Appendix 6 – Children receiving disability services**

#### Table 6 - Children under 9 by category of disability in 2011

Category of disability	Nos.	%
Intellectual Disability	3637	63%
Physical disability	646	11%
Hearing loss/deafness	34	0.5%
Visual disability	56	۱%
Speech and/or	700	12%
language disability		
Multiple disabilities	735	12.5%
Total	5808	100%

Source: Health Research Board

# Appendix 7 - Person hours required to complete a statutory assessment of need

Average hours required to complete average AON	Average hours required to complete more complex AON	Assessment as part of multi- disciplinary team	Typical number on team involved in multi- disciplinary team assessment	Total team hours	Clinical background
4		Yes	2	8	Clinical psychologist (senior)
14.5	26.5	No	NA	NA	Clinical psychologist (senior)
9		Yes	Determined by AO	NA	Clinical psychologist (senior)
10.5		Yes	Depends on referral question	NA	Clinical psychologist (senior)
14		No	NA	NA	Clinical psychologist (senior)
10	14	No	NA	NA	Clinical psychologist (senior) (school aged)
NA	NA	Yes	Depends on referral question	26*	Early Intervention Service Manager
4	6	Yes	Depends on referral question		Early Intervention Team Manager
3		Yes	2	6	Occupational Therapist

Table 7 – Person hours required to complete a statutory assessment of need
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Average hours required to complete average AON	Average hours required to complete more complex AON	Assessment as part of multi- disciplinary team	Typical number on team involved in multi- disciplinary team assessment	Total team hours	Clinical background
14		Yes	Depends on referral question	NA	Occupational Therapist
4	6	Yes	Depends on referral question	NA	Occupational Therapist
3	6	Yes	Depends on referral question	NA	Occupational Therapist
4	6	Yes	Depends on referral question	NA	Occupational Therapist
1.5		Yes	2	3	Occupational Therapist (senior)
40		No	NA	NA	Occupational Therapist (senior)
3		Yes	2	6	Occupational Therapist (senior)
4		No	NA	NA	Occupational Therapist (senior)
14		Yes	Depends on referral question	NA	Occupational Therapist (senior)
8**		No	NA	NA	Physiotherapist
4.5***		Yes	18	4	Physiotherapist
4		Yes	Depends on referral question		Principal Physiotherapist

Average hours required to complete average AON	Average hours required to complete more complex AON	Assessment as part of multi- disciplinary team	Typical number on team involved in multi- disciplinary team assessment	Total team hours	Clinical background
5		No	NA	NA	Principal Speech and
15	24	No	NA	NA	Language Therapist Psychiatrist (Children and Adolescent Mental Health team)
20	30	No	NA	NA	Psychologist (0-18)
2.5		No	NA	NA	Speech and Language Therapist (0 - 18)
6		Yes	Determined by AO	NA	Speech and Language Therapist (senior)
4		Yes	6	24	Speech and Language Therapist (senior)
7		Yes	Depends on referral question	NA	Speech and Language Therapist (senior)
21.5		No	NA	NA	Speech and Language Therapist (senior) (0 - 18)

Source: Figures based on answers given to National Disability Authority as part of interviews with assessors and service / team managers.

The figures above need to be treated with considerable caution. As is clear from the rest of this report, clinicians complete a variety of assessment types as part of the "statutory assessment of need" ranging from a screening assessment to a diagnostic work up. Therefore, these figures are not comparing like-for-like assessments.

\* The figure of 26 hours covers a fixed programme of intervention and hours to write a subsequent report (whether a statutory assessment of need report or not)

\*\* and \*\*\* The figure of 8 and 4.5 hours were given by the same physiotherapist who performs some statutory assessments of need as part of a team and some as unidisciplinary assessments.