

Report to the Minister of State with special responsibility

for Disability Issues at the Department of Health

As provided for under Section 13 of the Disability Act 2005

in respect of data collected in 2016

Based on data extracted from the Assessment Officer System Database

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SECTION A - BACKGROUND

1. Introduction

- 1.1. The Disability Act provides that a person who has, or may have, a disability, or a person advocating on their behalf may apply for an assessment of the health and education needs occasioned by their disability. The Act requires the HSE to appoint Assessment Officers to carry out or arrange the carrying out of Assessments of Need. The purpose of the assessments is to identify health and education needs occasioned by the disability and the services required to address these needs, without regard to the cost or the capacity to deliver these services.
- **1.2.** The Act requires the Assessment Officer to issue an Assessment Report, which includes a determination as to whether or not the individual has a disability, the nature and extent of the disability, a statement of the health and education needs and the services required to address these needs.
- 1.3. The HSE is also required to nominate Liaison Officers who are responsible for the preparation of Service Statements, following each assessment. In this regard, the HSE has appointed Liaison Officers under the Act in each area. The Service Statement outlines the services which will be delivered within available resources, when the service will be delivered and at what location.

2. Provisions of the Legislation and Regulations - Assessment Report

2.1. Section 8(7)(b)(iii) states that an Assessment Report should include: A statement of the services considered appropriate by the person or persons referred to in subsection (2) to meet the needs of the applicant and the period of time ideally required by the person or persons for the provision of those services and the order of such provision

3. Provisions of the Legislation and Regulations - Service Statement

- **3.1** Section 11(2) of the Disability Act states that a Service Statement should specify ...the health services or education services or both which will be provided to the applicant by or on behalf of the Executive or an education service provider, as appropriate, and the period of time within which such services will be provided.
- **3.2.** Section 11(6) states that:

A service statement shall not contain any provisions relating to education services where the subject of the statement is a child.

3.3. Section 11(12) states that:

A Liaison Officer shall arrange with the person or persons charged with delivering the services specified in the service statement for the delivery of the services at such times and in such manner as he or she may determine.

3.4. Paragraph 18 of the regulations state that:

The service statement shall be written in a clear and easily understood manner and it shall specify:

- a) The health services which will be provided to the applicant;
- b) The location(s) where the health service will be provided;
- c) The timeframe for the provision of the health service;
- d) The date from which the statement will take effect;
- e) The date for review of the provision of services specified in the service statement;
- f) Any other information that the Liaison Officer considers to be appropriate, including the name of any other public body that the assessment report may have been sent to under section 12 of the Act.

4. Provisions of the Legislation - Maintaining Records and Reporting

- **4.1.** The Disability Act 2005 requires certain records to be kept concerning the assessment of need process under Part 2 of the Act. Section 13(1) of the Act states that:
 - The Executive shall keep and maintain records for the purpose of:
 - (a) Identifying persons to whom assessments or services are being provided pursuant to this Part or the Act of 2004.
 - (b) Identifying those services and the persons providing the services pursuant to this Part.
 - (c) Specifying the aggregate needs identified in assessment reports which have not been included in the service statements.
 - (d) Specifying the number of applications for assessments made under section 9 and the number of assessments completed under that section.
 - (e) 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.
 - (f) Planning the provision of those assessments and services to persons with disabilities.
- **4.2.** Section 13(2) requires the Executive to submit a report 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.

5. Compliance with Reporting Obligations

- **5.1.** Since Part 2 of the Act was implemented in 2007, records have been kept in relation to 13(1) (a), (b), (d) and (f).
- **5.2.** Early in the process of implementation, a decision was taken in conjunction with the (then) Department of Health and Children that children's needs should be identified in terms of the desired outcomes and goals rather than in terms of a quantum of a particular service or discipline. This immediately presented difficulties in respect of fulfilling the obligations imposed by paragraph 13(1)(c).
- **5.3.** In respect of 13(1)(e), the developments to the IT system implemented in 2011, ensured that the processes around the production of the Service Statement by the Liaison Officer were recorded on the system. This ensures that each individual's file includes the details of the services that are identified in the Assessment Report as being required and those that they will actually receive. The age and category of disability (where known) of each applicant have been recorded since implementation in 2007.
- **5.4.** Converting need identified into a cost, as required under the Act, has proven problematic. Early reports to the Minister under section 13 of the Act have outlined suggested methodologies aimed at identifying the whole- time-equivalent (WTE) requirement indicated by a given shortfall identified in a particular service. However, this would require the identification of indicative case-loads for particular disciplines. There are no internationally accepted guidelines in this regard.
- **5.5.** A further issue arises from the fact that, increasingly, children are being referred to Early Intervention or School-Age Teams for team intervention, rather than being referred for intervention by individual disciplines. The practice of Assessment Officers identifying services in terms of individual disciplines is militating against this move towards more appropriate practice

SECTION B - BUILDING CHILDREN'S DISABILITY TEAMS

- 6. The Progressing Disability Services for Children and Young People Programme (0-18s Programme).
 - **6.1.** This programme aims to achieve a national unified approach to delivering disability health services in such a way that there is a clear pathway to services for all children regardless of where they live, what school they go to or the nature of their disability or delay.
 - **6.2.** Children should receive the health services they need as close to their home and school as possible. Some children may have their needs met by their local Primary Care services. An early intervention or a schoolage disability team will provide supports for all children with more complex needs in a defined geographic network area, regardless of the nature of their disability. These teams will be supported by specialist services when a high level of expertise is required.
 - **6.3.** The programme involves the reconfiguration of existing services for children with disabilities, in the statutory and non-statutory sectors, to form integrated, geographically-based teams.
 - **6.4.** While some areas in the country have been operating integrated children's disability teams for some time, 2013 saw the first areas to reconfigure their services under the auspices of the 0-18s Programme.
 - **6.5.** The 2013 mapping of resources has provided a clear picture of the staff available to the reconfiguration process.

- 7. National Disability Authority Report on the Practice of Assessment of Need under part 2 of the Disability Act 2005
 - **7.1.** The National Disability Authority (NDA) published its report in 2011. The conclusions included the following:

Section 10.3

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.

7.2. Although the report also found that there was no one solution to address the issues around the AON process. It would appear that the continued reconfiguration of existing services for children and young people with disabilities, in the statutory and non-statutory sectors, to form integrated geographically based teams (under the progressing children's disabilities programme) should improve the Assessment of Need process.

SECTION C - ACTIVITY DATA

8. Activity Data – 2016

8.1 The Activity Data in this report is an amalgamation of the four Quarterly "Assessment of Need Management Reports" for 2016. These are based on the data extracted from the Assessment Officer System Database.

Table 1. Number of Applications Received - Summary Totals

This table outlines the number of completed applications based on the date the HSE accepted the application. The report is grouped by Community Healthcare Organisation (CHO) Area.

5,727 completed applications were received by the HSE in 2016. This compares with 5,818 received in 2015, representing a decrease of -1.56%.

From the 1st June 2007 to 31st December 2016 a total of 37,453* completed applications have been received by the HSE.

СНО	Q1	Q2	Q3	Q4	Total for 2016
AREA 1	103	92	68	77	340
AREA 2	93	66	62	79	300
AREA 3	85	79	84	113	361
AREA 4	303	328	192	241	1064
AREA 5	110	129	110	162	511
AREA 6	60	46	43	50	199
AREA 7	427	308	241	251	1227
AREA 8	151	149	102	145	547
AREA 9	264	289	276	349	1178
Totals	1596	1486	1178	1467	5727

^{*}Late data entry may result in slight discrepancies from previous year.

Completed Application Data.

Figure 1 – Applications by CHO Area

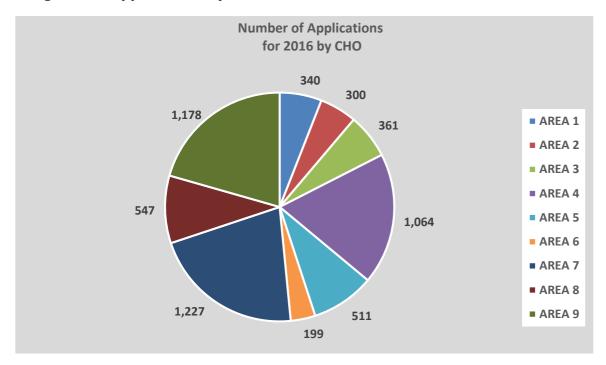
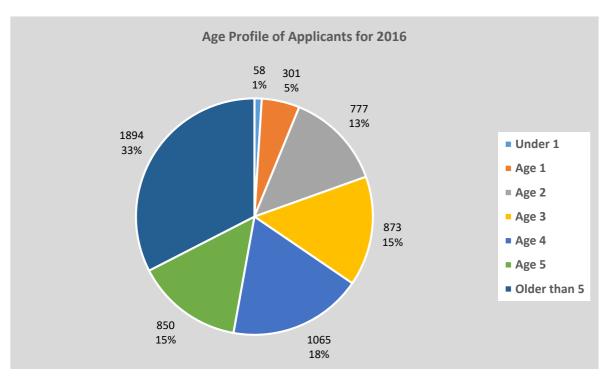


Figure 2 - Age Profile of Applicants



Number of Applications acknowledged

79% of applications received were acknowledged within the 2-week timeline.

Table 2. Number of Applications Commenced Stage 2.

According to defined statutory timelines all applications should commence stage 2 of the assessment process within 3 months of receipt of a completed application.

- 4,647 applications started stage 2 for the first time during 2016.
- 62% of those fell within the 3-month timeline.

СНО	Start Stage 2	*Within Timeline	% within timeline
AREA 1	285	268	94%
AREA 2	337	335	99%
AREA 3	373	371	99%
AREA 4	788	110	14%
AREA 5	446	274	61%
AREA 6	138	129	93%
AREA 7	1174	692	59%
AREA 8	441	340	77%
AREA 9	665	356	54%
Totals	4647	2875	62%

NOTE: Applicants that are re-entered into stage 2 are not included in the report

Table 3 Number of Assessment Reports Completed

'Within timeline' includes those assessments which have been completed within the timeframes set out in the Disability Act 2005 and accompanying Regulations. It also includes those assessments completed within a timeframe which has been extended due to 'exceptional circumstances' as provided for in Paragraph 10 of the Regulations. Reviewed reports are not included in this table.

The average duration of the assessment process per report completed in 2016 was 11.49 months.

СНО	No Disability	Disability	Total for 2016	Within Timeline	% Within Timeline
AREA 1	147	202	349	117	33.5%
AREA 2	66	215	281	218	77.6%
AREA 3	53	169	222	115	51.8%
AREA 4	74	338	412	55	13.3%
AREA 5	41	198	239	34	14.2%
AREA 6	4	69	73	19	26.0%
AREA 7	105	559	664	46	6.9%
AREA 8	129	274	403	111	27.5%
AREA 9	67	482	549	17	3.1%
Totals	602	2506	3108	732	23.6%

^{* &#}x27;Within Timeline' refers to applications starting stage 2 strictly within the 3 month timeline. Some applications are late starting stage 2 due to mitigating circumstances e.g. 'Application on Hold', 'Parental Request'.

Category of Disability (3,108 Assessment Reports completed) 53, 2% Attention Deficit Hyperactivity Disorder 228, 7% 9, 0% 166, 5% Autistic Spectrum Disorder ■ Global Developmental Delay ■ Intellectual 772, 25% ■ Mental Health 444, 14% ■ No Category Specified At This Stage None 94, 3% Physical 72, 2% ■ Primary Speech & Language 49. 2% 122. 4% 495, 16% Sensory ■ Specific Learning Disability 604, 20% ■ Multiple

Figure 3 - Reports Completed by Disability

N.B. Applicants with more than 1 recorded disability appear in the 'Multiple' category only.

Table 4 Applications Overdue to commence Stage 2 on 31st December 2016.

998 Applications due to commence stage 2 by the end of 2016 had not done so.

СНО	Overdue	<1 month	1 - 3 Months	>3 Months
AREA 1	0	0	0	0
AREA 2	0	0	0	0
AREA 3	0	0	0	0
AREA 4	768	85	109	574
AREA 5	27	17	0	10
AREA 6	2	1	1	0
AREA 7	18	8	3	7
AREA 8	7	3	1	3
AREA 9	176	32	63	81
Totals	998	146	177	675

Note: Applications that were placed on hold are not included in this report.

Table 5 Applications overdue for Completion on 31st December 2016 (1)

Applications are deemed 'Overdue' if it is more than 6 months since the application was accepted by the HSE and there is no record of an Assessment Report being sent to the Liaison Officer or to the Applicant. This overdue figure does not include applications that have been put on hold, are closed or are ineligible for Assessment.

3,960 applications were overdue for completion at end 2016 with 397 of these on the grounds of there being exceptional circumstances as provided for in paragraph 10 of the regulations.

СНО	Total Overdue ¹	Overdue/ Exceptional Circumstances ²	Overdue/ No Exceptional Circumstances
AREA 1	92	15	77
AREA 2	8	7	1
AREA 3	112	47	65
AREA 4	1732	149	1583
AREA 5	293	53	240
AREA 6	38	2	36
AREA 7	826	40	786
AREA 8	261	24	237
AREA 9	598	60	538
Totals	3960	397	3563

¹All assessment reports that were not completed within 6 months of application or within 3 months of Start Stage 2 and before the end of the quarter are included in this report. ²The number of Assessment Reports for which an extended time-frame was negotiated with the parent on the grounds of there being exceptional circumstances as provided for in paragraph 10 of the regulations. Consent to extension is only valid if agreed extension date has not already passed.

Table 6 Applications overdue for completion on 31st December 2016 (2)

- Of the 3,960 applications that are overdue, 2,902 (73%) are overdue for longer than 3 months.
- Months overdue are calculated based on the statutory timelines of 3 months from start stage 2 and no more than 6 months from the application date. This overdue figure does not include applications that were put on hold, are closed or are ineligible for Assessment.

СНО	Overdue	<1 month	1 - 3 Months	>3 Months
AREA 1	92	21	21	50
AREA 2	8	5	0	3
AREA 3	112	31	35	46
AREA 4	1732	117	215	1400
AREA 5	293	40	66	187
AREA 6	38	7	15	16
AREA 7	826	68	155	603
AREA 8	261	33	42	186
AREA 9	598	71	116	411
Totals	3960	393	665	2902

Table 7 Service Statements Completed 2016

This table counts Service Statements dispatched to the applicant during 2016. It does not include reviewed or modified service statements. The timeline is calculated from the date the Assessment Report was sent to the Liaison Officer to the date the Service Statement is dispatched to the applicant. The Statutory Timeline for this process is 1 month.

2,436 Service Statements were dispatched to the applicant during 2016 with 62% dispatched within the 1-month timeline.

СНО	Total	Within Timeline	% within timeline
AREA 1	140	101	72.1%
AREA 2	209	206	98.6%
AREA 3	183	93	50.8%
AREA 4	246	167	67.9%
AREA 5	151	105	69.5%
AREA 6	29	1	3.4%
AREA 7	555	348	62.7%
AREA 8	279	138	49.5%
AREA 9	644	348	54.0%
Totals	2436	1507	61.9%

8.1. Since a High Court ruling of December 2009, the effect of which was to open eligibility to children born after 1st June 2002 who are suspected of having a disability, the number of children over five years of age, and therefore of school-going age, has risen steadily as a percentage of all applications received. At the end of 2011, the figure stood at 26%, at the end of 2015, the percentage was 47%. Table 8 shows the percentage to be 50% at the end of 2016.

Table 8 Applicants 5 years and over				
2016	Total	5 yrs & over	%	
Q1	1596	816	51	
Q2	1486	823	55	
Q3	1178	537	46	
Q4	1467	692	47	
TOTAL	5727	2868	50	

8.2. Table 9 provides some comparisons of activity between 2015 and 2016.

	Table 9 Comparison of Activity 2015-2016						
Applications Received Variance Assessment Reports Produced Variance						Variance	
HSE	2015	2016	%	2015 2016		%	
TOTAL	5,818	5,727	-1.6	3,318	3,108	-6.3	

SECTION D - IDENTIFYING THE RESOURCE REQUIREMENT

Section 13 (2) requires the Executive to submit a report 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.

9. Resource Availability

- **9.1.** It has been determined that work should continue on building the evidence-base necessary to inform the allocation of resources which may become available in the future. It is clear that this is a more complex process than originally envisaged by the drafters of legislation.
- **9.2.** The following sections outline the potential components of that evidence base. It must be remembered that there continues to be a lack of international consensus on what constitutes an indicative case-load for each of the disciplines involved or, indeed, for a team of clinicians offering services to a particular population.

10. WTEs Required for the Assessment of Need Process

- **10.1.** At the time Part 2 of the Act was commenced it was understood that the Assessment of Need process was only open to children up to the age of 5 years and the WTE projections were based on that age-cohort and an estimated disability prevalence rate of 5%. Since a High Court ruling of December 2009, the effect of which was to open eligibility to children born after 1st June 2002, the number of children over five years of age, and therefore of school-going age, has risen steadily as a percentage of all applications received.
- 10.2. Eligibility for Assessment of Need now includes children aged 14 years. These children will have attended school for up to 10 years and it had originally been anticipated that these children would be assessed under the terms of the Education for Persons with Special Educational Needs Act 2004 (EPSEN). The relevant sections of this Act have not been commenced. No additional resources have been identified to meet the resulting increase in demand for Assessment of Need.

11. 0-18s Programme

- 11.1 As previously mentioned in section 6, an exercise was completed in 2013 which mapped the resources in terms of therapy WTEs available in each HSE Area. This has provided the base-line information required to conduct the necessary discussions on the reconfiguration of resources into Children's Disability teams under the auspices of the 0-18s programme.
- 11.2 Since 2014, the roll out of the Progressing Disability Services for Children and Young People (0-18s) Programme has entailed targeted investment of €14m and the provision of 275 additional therapy staff, to increase services for children with all disabilities. In 2016, funding of €4m was announced in the National Service Plan to provide 75 therapy posts. €4m was also allocated to Primary Care in the 2016 Service Plan to facilitate the recruitment of 83 Speech and Language therapists to address waiting lists.
- **11.3** As new teams are established in the coming years and they begin to collect data, the shortfalls in terms of disciplines required to populate the teams and information on the size of the population which can be catered for, will become clearer.
- 11.4 In the light of the fact that the 0-18s Programme has been demonstrated to have a significant effect on the efficiency and effectiveness of the operation of the assessment of need process, the information contained in this report will serve as a useful base-line. As teams are established in the coming years, it will be possible to measure the effect they are having in particular areas.
- 11.5 In completing assessment reports clinicians identify the services required to meet the needs of the child. Table 10 shows the frequency (ranked nationally) with which requirements for certain services have been identified. These figures are based on Assessment of Need reports completed in 2016. During this period 2,626 children determined to have a disability under the Act had service requirements identified. It should also be noted that a significant proportion of children not determined to have a disability as defined by the Act will also require access to health and social care services.

Table 10 Service Requirements Identified in Completed Reports

Service Requirements 2016	Service Totals 2016	Frequency of Services Indicated
Speech and Language Therapy	1831	69.73%
Occupational Therapy	1741	66.30%
Psychology	1388	52.86%
Physiotherapy	536	20.41%
Paediatric Services (Hospital/Community)	450	17.14%

In the main these figures represent new referrals to the identified services. In all cases, every effort is made to ensure that these services are provided in a timely way.

11.6 Through the Progressing Disability Services for Children and Young People Programme (0-18) the HSE has identified resourcing deficits across a range of services required by children and young people with disabilities. For the purposes of this report estimated staffing ratios have been used to determine the staffing requirements to meet the identified need. It should be noted that there are no nationally or internationally accepted guidelines in this regard.

Table 11 Additional staff required to meet the identified need

Service	Suggested ratio Staff:Service User	Total	Cost*
Speech &Language Therapy	1:40	46	€2.16m
Occupational Therapy	1:40	44	€2.06m
Psychology	1:100	14	€1.02m
Physiotherapy	1:40	13	€0.63m

^{*} The cost is estimated based on the mid-point of the basic grade scale

12. Conclusion

- **12.1** There are shortcomings in the Assessment of Need process with additional applications being received from an increasing age cohort of children.
- **12.2** There is a difference between the identified needs of children (as outlined in their Assessment Reports) and the services which are being provided to them.

This can be due to a range of factors including:

- *Staffing levels
- *Demand levels
- *Availability of specialist support etc.
- **12.3** Early intervention is a key component to supporting children presenting with challenges, and is supported by international research.
- 12.4 The HSE recognises that it faces significant challenges in respect of meeting the statutory time-frames which apply to the assessment of need process. Targeted action plans have been in place since early 2011 and measures have included prioritising assessments, holding additional clinics, and reconfiguring resources to target areas of greatest need. In addition, therapists in private practice have been contracted to conduct assessments, where appropriate. Guidance Notes have been issued to Assessment Officers for use when contracting private practitioners to undertake assessments under the Disability Act, to help ensure that children are being assessed in line with the provisions of the legislation and in line with the standards laid down by HIQA.
- **12.5** While any delay in assessment or intervention for any child is not desirable, the assessment process under the Disability Act can take place in parallel with any intervention which is identified as necessary. The fact that a child is waiting for their statutory assessment to be completed should not be interpreted as meaning that the child is necessarily waiting for necessary, identified interventions. Direct referral to services is a consideration for referrers, and is in keeping with the reconfiguration of 0-18 Programme.
- **12.6** A 'Working Group' was established to examine the issues/current practice involved in the continued poor performance against targets in Assessment of Need activity with a view to identifying best practice and issuing recommendations and updated guidelines to improve performance.
- **12.7** Figures represented in this report <u>do not</u> take account of those children who are accessing services outside of the AON process.
- **12.8** All services carry a significant clinical caseload as well as managing the requirement to provide Assessments of Need under the Disability Act 2005.
- **12.9** In the light of the fact that the **Progressing Disability Services (0-18s Programme)** has been demonstrated to have a significant effect on the efficiency and effectiveness of the operation of the assessment of need process, the information contained in this report will serve as a useful base-line. As teams are established in the coming years, it will be possible to measure the effect they are having in particular years.
- **12.10** There were 56 Children's Disability Network Teams in place by end 2016, with the total number of teams expected to be 129. Local

Implementation Groups (LIGs) have been established in each Community Healthcare Organisation with the role of ensuring the implementation of PDS plans.

12.11 The HSE will focus on driving implementation of the **Progressing Disability Services** Programme as a means to improve access to services and consequently the Assessment of Need process in the longer term.