

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 2017

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 school-age 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. This continued in 2017.
 - **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 - 2017

8.1 The Activity Data in this report is an amalgamation of the four Quarterly "Assessment of Need Management Reports" for 2017. 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.

5,839 completed applications were received by the HSE in 2017. This compares with 5,727 received in 2016, representing an increase of 2%.

From the 1st June 2007 to 31st December 2017 a total of 43,521* completed applications have been received by the HSE.

СНО	Q1	Q2	Q3	Q4	Total for 2017
AREA 1	94	76	59	42	271
AREA 2	90	88	62	78	318
AREA 3	131	110	97	126	464
AREA 4	312	261	229	252	1054
AREA 5	179	124	106	88	497
AREA 6	59	55	40	60	214
AREA 7	332	332	263	291	1218
AREA 8	190	175	165	136	666
AREA 9	341	326	208	262	1137
Totals	1728	1547	1229	1335	5839

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

Completed Application Data.

Figure 1 – Applications by CHO Area

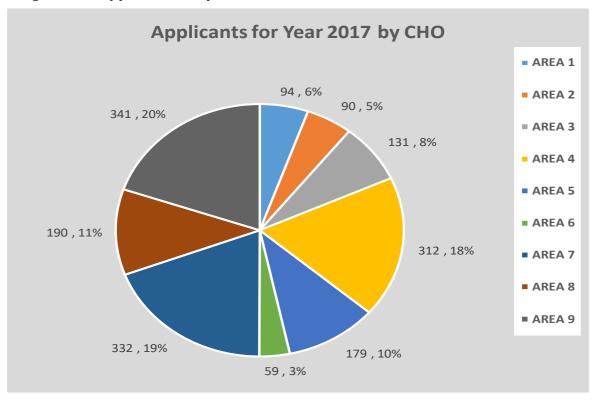
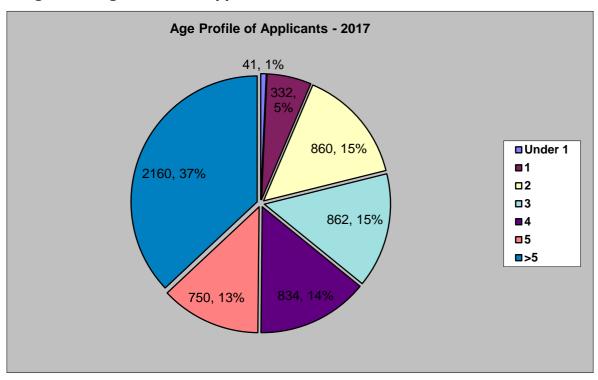


Figure 2 - Age Profile of Applicants



Number of Applications acknowledged

80% 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.

- 5,312 applications started stage 2 for the first time during 2017.
- 69% of those fell within the 3-month timeline.

СНО	Start Stage 2	*Within Timeline	% within timeline
AREA 1	270	245	91%
AREA 2	318	314	99%
AREA 3	449	441	98%
AREA 4	1351	459	34%
AREA 5	358	180	50%
AREA 6	167	133	80%
AREA 7	1047	706	67%
AREA 8	549	382	70%
AREA 9	803	475	59%
Totals	5312	3335	69%

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

Table 3 Number of Assessment Reports Completed

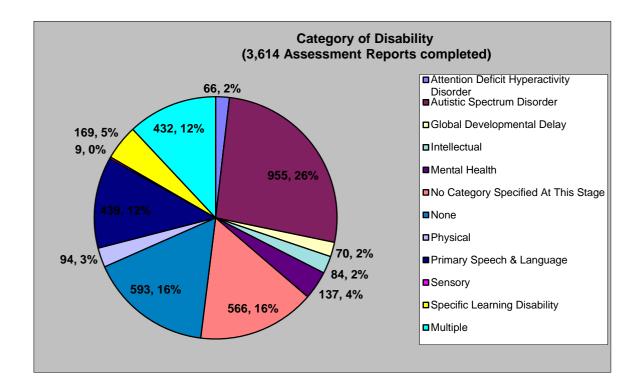
'Within timeline' includes those assessments which have been completed within the timeframes set out in the Disability Act 2005 and accompanying Regulations. It also includes those assessments completed within a timeframe which has been extended due to 'exceptional circumstances' as provided for in Paragraph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

The average duration of the assessment process per report completed in 2017 was 12.90 months.

СНО	No Disability	Disability	Total for 2017	Within Timeline	% Within Timeline
AREA 1	23	151	174	71	40.8%
AREA 2	74	175	249	213	85.5%
AREA 3	73	227	300	189	63.0%
AREA 4	61	195	256	56	21.9%
AREA 5	42	208	250	52	20.8%
AREA 6	1	113	114	14	12.3%
AREA 7	195	1014	1209	63	5.2%
AREA 8	108	287	395	148	37.5%
AREA 9	102	565	667	109	16.3%
Totals	679	2935	3614	915	25.3%

^{* &#}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'.

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 2017.

232 Applications due to commence stage 2 by the end of 2017 had not done so.

СНО	Overdue	<1 month	1 - 3 Months	>3 Months
AREA 1	13	5	8	0
AREA 2	0	0	0	0
AREA 3	0	0	0	0
AREA 4	11	0	2	9
AREA 5	92	21	45	26
AREA 6	0	0	0	0
AREA 7	4	3	1	0
AREA 8	23	5	14	4
AREA 9	89	20	21	48
Total	232	54	91	87

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

Table 5 Applications overdue for Completion on 31st December 2017 (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.

4,312 applications were overdue for completion at end 2017 with 245 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	178	6	172
AREA 2	41	2	39
AREA 3	184	72	112
AREA 4	1886	87	1799
AREA 5	414	33	381
AREA 6	54	2	52
AREA 7	603	2	601
AREA 8	357	7	350
AREA 9	595	34	561
Total	4312	245	4067

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 2017 (2)

- Of the 4,312 applications that are overdue, 3,281 (76%) 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	178	16	37	125
AREA 2	41	16	18	7
AREA 3	184	57	47	80
AREA 4	1886	58	105	1723
AREA 5	414	43	64	307
AREA 6	54	14	15	25
AREA 7	603	84	131	388
AREA 8	357	53	84	220
AREA 9	595	47	142	406
Total	4312	388	643	3281

Table 7 Service Statements Completed 2017

This table counts Service Statements dispatched to the applicant during 2017. 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.

2,455 Service Statements were dispatched to the applicant during 2017 with 50.8% dispatched within the 1-month timeline.

СНО	Total	Within Timeline	% within timeline
AREA 1	118	62	52.5%
AREA 2	166	158	95.2%
AREA 3	202	129	63.9%
AREA 4	85	12	14.1%
AREA 5	193	95	49.2%
AREA 6	71	5	7.0%
AREA 7	872	370	42.4%
AREA 8	210	79	37.6%
AREA 9	538	336	62.5%
Total	2455	1246	50.8%

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 2016, the percentage was 50%. Table 8 shows the percentage to be 50% at the end of 2017.

Table 8 Applicants 5 years and over						
2017	2017 Total 5 yrs & over %					
Q1	1728	852	49			
Q2	1547	804	52			
Q3	1229	570	46			
Q4	1335	684	51			
TOTAL						

8.2. Table 9 provides some comparisons of activity between 2016 and 2017.

	Table 9 Comparison of Activity 2016-2017					
Applications Received Variance Assessment Reports Produced Variance					Variance	
HSE	2016	2017	%	2016 2017		%
TOTAL 5,727 5,839 +2 3,108 3,614 +16.3						+16.3

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 15 years. These children will have attended school for up to 11 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 health 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.
- 11.3 The HSE introduced a National Policy on Access to Services for Children & Young People with Disability & Developmental Delay. Implementation of this policy will ensure that children are directed to the appropriate service based on the complexity of their presenting needs rather than based on diagnosis. Many children who have support needs can be effectively supported within mainstream health services. This policy provides a single point of entry, signposting parents and referrers to the most appropriate service (Primary Care for non-complex functional difficulties and Children's Disability Network Teams for complex functional difficulties).
- **11.4** 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.
- 11.5 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.
- 11.6 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 2017. During this period 2,986 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 2017	Service Totals 2017	Frequency of Services Indicated
Speech and Language Therapy	2254	75.5%
Occupational Therapy	2227	74.6%
Psychology	1921	64.3%
Physiotherapy	683	22.9%
Paediatric Services (Hospital/Community)	482	16.1%

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.

11.7 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 is 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	56	€2.79m
Occupational Therapy	1:40	56	€2.79m
Psychology	1:100	19	€1.43m
Physiotherapy	1:40	17	€0.74m

^{*} 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 Substantial work was undertaken during 2017 to address waiting times for Assessment of Need under the Disability Act (2005). All Community Healthcare Organisations developed improvement plans to address areas of non-compliance with the statutory time frames. Significant progress was made in addressing waiting times at "Stage one" of the process. Additional resources were also put in place in areas of particular difficulty.
- **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** A total of 56 networks of the 138 network teams planned are in place. The appointment of Children's Disability Network Managers has been identified as a critical enabler to facilitate the continued roll out of this programme. A Forum was established comprising representatives from Impact, HSE Corporate Employee Relations and HSE Disability Operations Team to progress the implementation and recruitment of these posts. Plans are now in place to commence recruitment.
- **12.11** A team of three National Disability Specialists (NDS) is now in place working with CHOs on a CHO basis in relation to Children's Disability Services. A specialist training and support resource has been made available to the NDS team for deployment at CHO level. This will enable capacity building with frontline professionals.
- **12.12** 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.
- 12.13 In addition, a revised Standard Operating Procedure for Assessment of Need has been developed to ensure that there is a standardised approach to assessment across all areas. It is intended that this procedure will be implemented from 1st April 2018. The procedure addresses the issue of eligibility for Assessment of Need and aligns this with the National Policy on Access to Services for Children & Young People with Disability & Developmental Delay. The implementation of the Standard Operating Procedure for Assessment of Need is intended to support children with disabilities to access timely assessment and appropriate intervention.