



Oifig an Cheannaire Oibríochtaí,
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
31-33 Sráid Chaitríona, Luimneach.

Office of the Head of Operations,
Disability Services/Social Care Division,
31-33 Catherine Street, Limerick.

T: 00353 (0) 61 483369
Suíomh Gréasáin/Website: <http://www.hse.ie>

14th March 2022

Deputy David Cullinane,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: david.cullinane@oireachtas.ie

Dear Deputy Cullinane,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary questions, which were submitted to this department for response.

PQ 11583/22

To ask the Minister for Health the average length of time it took to complete an assessment of need before January 2020; and the way this has changed since the introduction of the standard operating procedure; and if he will make a statement on the matter.

PQ 11586/22

To ask the Minister for Health if he will detail each list to which a child may be referred or transferred following the completion of an assessment of need and the issuing of a service statement for further assessment; and if he will make a statement on the matter.

PQ 11587/22

To ask the Minister for Health the number of children who received an assessment of need in 2020 or 2021 who were referred for further assessment and subsequently diagnosed with ASD; and if he will make a statement on the matter.

PQ 11148/22

To ask the Minister for Health the number of children that have been recommended for further diagnostic assessment following the completion of an assessment of need by community disability network team and by the length of wait for further assessment; and if he will make a statement on the matter.

PQ 11882/22

To ask the Minister for Health the number of persons on further diagnostic assessment waiting lists by CHO at the end of 2021 and at the latest available data point broken down age and by the length of waiting time by age in tabular form.

PQ 11129/22

To ask the Minister for Health the number of persons on assessment of needs waiting lists by children's disability network team including length of wait; the number of persons on subsequent diagnostic assessment, for example ASD assessment lists by children's disability network team; and if he will make a statement on the matter

PQ 11130/22



To ask the Minister for Health the number of persons on ASD diagnosis waiting lists by age and length of wait time. -

HSE Response

Since the Disability Act commenced in June 2007, the HSE has endeavoured to meet its legislative obligations under the Act. However, as a consequence of a High Court ruling of December 2009, the effect of which was to open eligibility to all children born after 1st June 2002, the number of children aged five and over, and in addition of school-going age, has risen steadily as a percentage of all applications received. At the end of 2011, the figure stood at 26%, while throughout 2021, this figure averaged 53%. This is a reflection that the AON process is an accumulative process in terms of numbers of children seeking access. However, it is acknowledged that the numbers of assessments overdue for completion remain high.

Activity for the year indicates that there has been significant progress in the number of Assessment of Need reports completed during the year, 8,353 by year end. This has led to a significant reduction in the total number of applications 'overdue for completion', which now stands at 1,793 (excluding those applications 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). See Table 1.

(Table 1) Applications overdue for completion

CHO	Total Overdue ¹	Overdue/ Exceptional Circumstances ²	Overdue/ No Exceptional Circumstances
AREA 1	36	9	27
AREA 2	21	1	20
AREA 3	37	21	16
AREA 4	711	56	655
AREA 5	90	10	80
AREA 6	65	5	60
AREA 7	176	0	176
AREA 8	203	9	194
AREA 9	647	82	565
Total	1986	193	1793

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

The increase in activity in 2021 can be attributed to the additional funding allocated to the AON process via Slaintecare. This has been utilised to provide additional assessments through a range of options including overtime for existing staff and private procurement. The total number of overdue AONs has reduced by 63% since this additional funding was allocated.

Table 2 below outlines the the average duration (in months) of the assessment process per report completed in each quarter of 2019 and after the introduction of the SOP in 2020 and 2021.

Table 2

	2019	2020	2021
Q1	21.48	19.48	17.36
Q2	19.12	19.06	16.68
Q3	19.13	19.17	17.22
Q4	19.45	19.83	14.96

The Disability Act (2005) requires the HSE to deliver a standardised approach to Assessment of Need. Since the implementation of Part 2 of the Act in June 2007 clinicians have erred on the side of caution and undertaken a suite of assessments for each applicant. Consequently, some children waited several years for their Assessment of Need, often on the waiting list for the incorrect service. Furthermore, this focus on assessment was delivered to the



detriment of intervention. Many services targeted all of their resources towards assessment and were then unable to deliver intervention. The HSE decision to define an AON as a Preliminary Team Assessment (PTA) is intended to ensure that children receive timely, streamlined assessments that identify the child's immediate needs and facilitates the provision of follow up intervention and support.

While a guideline timeframe for a PTA is provided, this is not prescriptive. The format for each PTA is a matter for the assessing clinicians.

The guidance for assessors included in the SOP suggests that this assessment should include;

- Discussion with parents / guardians to establish case history information, explore their concerns and profile their goals for the child
- Assessment of the child's needs through the following as appropriate
 - Informal observation
 - Play based assessment
 - Administration of screening assessment tools
 - Administration of formal or informal assessment tools
 - Discussion with the child / young person

Furthermore, the guidance also states that no family should leave the clinic without some strategies to support the child / young person.

Some teams may have scheduled routine assessments with children and families that coincide with the timeframe for that child's AON. In such cases teams are not expected to duplicate and may complete their AON report based on the scheduled assessment.

The Key Performance Indicators associated with the AON process require teams to achieve compliance with the statutory timeframes provided for in the Disability Act. The length of time allocated to each appointment is not measured.

Community Healthcare Organisations have reported the following PTA activity for 2021:

	Total PTA Activity 2021				
	No. of PTAs completed	No. referred for intervention	% referred for intervention	No. referred for further Ax	% referred for further Ax
CHO1	366	356	97%	309	84%
CHO2	132	130	98%	121	92%
CHO3	375	242	65%	330	88%
CHO4	554	542	98%	252	45%
CHO5	139	138	99%	84	60%
CHO6	207	155	75%	111	54%
CHO7	1407	1300	92%	551	39%
CHO8	719	490	68%	411	57%
CHO9	1052	884	84%	511	49%
	4951	4237	86%	2680	54%

While this data indicates that there is substantial variation in outcomes across the 9 CHO areas 86% of children are being referred for intervention on the basis of these assessments. This represents a significant improvement in the pathway to intervention for children and their families. The variance in the proportion of children referred for further assessment will be examined as part of the AON review.

It should also be noted that children do not need to go through the Assessment of Need process for diagnostic assessments or further diagnostic assessments. Assessment is a core function of the work of all clinicians.

ASD Service Improvement Board



Disability services are provided based on the presenting needs of an individual rather than by the diagnosis of the individual or the actual type of disability. Services are provided following individual assessment according to the person's individual requirements and service needs. Approximately 60% of applicants for Assessment of Need are identified as requiring a diagnostic ASD assessment.

Following publication of the ASD Service Review in 2017, a Service Improvement Programme for the Autistic Community has commenced. This has two work streams:

1. Assessment and Pathway Working Group:

The Assessment and Pathways working group aims to develop a Standardised Assessment approach for use in all services dealing with the assessment of those with Autism to ensure that every assessment is of an acceptable and agreed standard, regardless of which service is being accessed. In addition, it seeks to agree a standardised service user journey and the implementation of a consistent core service offering across those providing services to people with Autism, including adults.

The Working Group, including people with lived experience of autism, has consulted widely with key stakeholders in the design and formulation stage of the project; this is particularly important in the context of the implementation of a tiered approach to assessment.

Its main work focus has been to:

- Agree an operational model for a tiered approach to Autism Assessment through developing clear and functioning pathways to services.
- This will contribute to the National Clinical Programme for People with Disabilities (NCPD) producing a Model of Service (including initial and ongoing assessment) for people with Autism, with appropriate sign off through the governance procedures of the NCPD.
- An implementation plan to include training which takes cognisance of existing policies of the HSE
- Social Care/Primary Care/Mental Health Policy Training material to support the agreed approach to Autism Assessment
- The development, where required, of processes or supporting protocols to underpin

A draft document which sets out the assessment protocol for both children and adults is being piloted in three CHOs (2, 7 & 9). It will then be evaluated to inform the further iteration and development of the protocol.

2. Awareness Working Group:

The Report of the Review of the Irish Health Services for Individuals with Autism showed that the information available to the Autistic community, Family Members, Carers and Service providers was limited, and inconsistent from region to region and did not always reflect current understanding and approaches. The HSE, through the work of the Awareness Working Group have taken a comprehensive approach to addressing this, and is reviewing existing content, seeking the views of the Autistic Community, Family Members, Carers and Service Providers on this content, and working to ensure it can be produced and made accessible to people all over the country, online and in print. This quality process has been progressing and will continue into next year.

The Awareness Stream of the programme is designed to respond to the call for greater clarity amongst Clinicians and Service Providers regarding both Autism and the supports available to people with Autism.

- There are a number of individuals with the lived experience participating in this group.
- The availability of comprehensive accessible information relating to Autistic people, their families, and healthcare workers working in the field
- The development of an online knowledge hub combined with a helpline aimed at providing contemporary information in relation to :a) location and types of services, b) tools and resources for service users, their families and clinicians and c) signposting to other essential community, voluntary and statutory based supports and services.

The outputs from this work will have wider application and benefits across all disability services.

National Information Management System for the CDNTs



With regard to waiting lists for services provided by children's disability network teams, historically the number of children waitlisted for children's disability services provided by section 38 and section 39 providers has not been available nationally. The establishment of CDNTs will facilitate the collection of this data. A National Management Information System for all 91 CDNTs is in development and when implemented, will provide current data on waiting lists for all CDNTs. In the interim, manual data collection is on-going and will provide information to the local areas regarding the number of children waiting for each CDNT.

Overall Reform of Children's Disability Services

The implementation of the Progressing Disability Services for Children & Young People (PDS) programme is agreed Government and HSE policy. This policy supports the reconfiguration of children's disability services to provide equitable, child and family centred services based on need rather than diagnosis. This aligns with the UN Convention on the Rights of People with Disabilities.

The Progressing Disability Services for Children and Young People (PDS) model addresses the previous inequity in service provision whereby there may have been an excellent service for some children and little or no service for others. This variance may have been linked to diagnosis, age group or geography. Under the PDS programme children's disability services are changing from diagnosis based to needs based, so that all children with a disability or developmental delay have access to the right service based on their needs no matter where they live.

PDS is a significant change programme for the provision of services and supports for children from birth to 18 years of age, in line with Sláintecare and the Programme for Government, in order to:

- Provide a clear pathway and fairer access to services for all children with a disability
- Make the best use of available resources for the benefit of all children and their families
- Ensure effective teams are working in partnership with families and with education staff to support children with a disability to reach their full potential.

PDS aligns with two clear objectives of The Sláintecare Report to:

- Provide the majority of care at or as close to home as possible
- Create an integrated system of care with healthcare professionals working closely together.

The National Policy on Access to Services for Children & Young People with Disability & Developmental Delay ensures that children are directed to the appropriate service based on the complexity of their presenting needs rather than based on diagnosis. Many children with a disability 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).

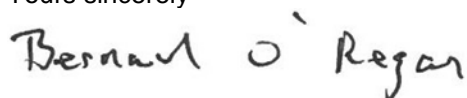
Children's Disability Network Teams (CDNTs)

In 2021, ninety one Children's Disability Network Teams (CDNTs) were established to provide services and supports for all children with complex needs within a defined geographic area.

CDNTs are teams of health and social care professionals, including nursing, occupational therapy, psychology, physiotherapy, speech and language therapy, social work and others. The team will work closely together in a family centred model, focusing on the child's and family's own priorities. Every child with complex needs will have access to a team, regardless of the nature of their disability, where they live, or the school they attend.

Children and their families will have access to the full range of services and supports of the CDNT according to their individual needs. This includes universal, targeted and specialist supports, such as individual therapeutic intervention and access to specialist consultation and assessment when needed. Supports will be provided as is feasible in the child's natural environments - their home, school and community.

Yours sincerely



Bernard O'Regan



**Head of Operations - Disability Services,
Community Operations**

