

Oifig an Stiúrthóir Cúnta Náisiúnta,

Foireann Míchumais Náisiúnta, An Chéad Urlár - Oifigí 13, 14, 15, Àras Phlásóg na Rós, Coimpléasc Gnó na hOllscoile, Páirc Náisiúnta Teicneolaíochta, Caladh an Treoigh, Luimneach.

Office of the Assistant National Director,

National Disability Team, First Floor- Offices 13, 14, 15, Roselawn House, University Business Complex, National Technology Park, Castletroy, Limerick.

29th October 2024

Deputy Pauline Tully, Dail Eireann, Leinster House, Kildare Street, Dublin 2. E-mail: <u>pauline.tully@oireachtas.ie</u>

Dear Deputy Tully,

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

PQ: 41091/24

To ask the Minister for Children; Equality; Disability; Integration and Youth the number of children on all waiting lists under the children disability network teams, including the number waiting on an initial contact, the number waiting on an assessment of needs, and the number waiting on therapy supports, in tabular form. -

HSE Response

National Access Policy

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 i.e. Primary Care for non-complex functional difficulties and Children's Disability Network Teams for complex functional difficulties arising from their disability. Children with ASD may access supports from a Children's Disability Network Team or from Primary Care or from Child and Adolescent Mental Health Services (CAMHS) depending on the complexity of their needs.

It is important to note that children do not require an Assessment of Need as defined by the Disability Act (2005) in order to access a CDNT or Primary Care service or Mental Health Service They can be referred by a healthcare professional or parent/carer to the or to Primary Care.

Childrens Disability Network Teams

In 2021, the remainder of ninety-one multidisciplinary CDNTs, now 93 CDNTs, were established in 96 Network areas to provide services and supports for all children, from birth to 18 years of age, with complex needs, within a defined geographic area.



The model of service for all CDNTs is family-centred and based on the needs of the child. This includes universal, targeted and specialised supports and interventions, as appropriate to the individual child and family. It is based on the objectives of empowering and supporting parents and others who are with the child on a daily basis to facilitate the child's developmental needs.

The CDNTs are currently providing services and supports for over 42,000 children and strategies and supports for urgent cases on the waitlist where staffing resources allow. However, there are significant challenges for CDNTs including:

- Significant staffing vacancies
- Growth in numbers of children with complex need as a result of their disability.
- Growth in demand for Assessment of Need, diverting further resources away from interventions

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Roadmap for Service Improvement 2023 – 2026, Disability Services for Children and Young People

The HSE's Roadmap for Service Improvement 2023 – 2026, Disability Services for Children and Young People is a targeted Service Improvement Programme to achieve a quality, accessible, equitable and timely service for all children with complex needs as a result of a disability and their families.

The Roadmap, now in its implementation phase, has established four Working Groups which report into a Service Improvement Programme Board every month which in turn reports to the Roadmap Oversight Group chaired by the Minister of State, Ann Rabbitte.

<u>Working Group 3: **Workforce**</u> – has responsibility for developing a recruitment strategy for all CDNTs regardless of the Lead Agency; Retention of existing CDNT staff; Deployment of Students/Trainees/New Graduates; and Development of Existing Staff.

Waiting List for the Childrens Disability Services

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 in 2021 has facilitated the collection of this data. A National Management Information System for all 93 CDNTs is being rolled out and when implemented, will provide current data on waiting lists and other details for all CDNTs.

Pending full roll-out, manual data collection is on-going. The table below is the most recent validated data available. end of September 2024 activity reports. This shows the number of children that are waiting for an initial contact with a CDNT in the 9 CHO Areas. Please note that the CDNTs do not collect activity data by individual discipline (such as SLT, Physiotherapy, OT etc) as this does not align with the interdisciplinary model of care. In this context, therapy-specific data is not available.

Status report	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9
No of children waiting 0-3 months for an initial contact									
@month end	97	172	216	164	99	47	154	232	56
No of children waiting 4-6 months for an initial contact									
@month end	61	146	208	122	90	88	181	176	57

No of children waiting 7-12 months for an initial contact @month end	29	188	334	147	134	118	340	370	200
No of children waiting over 12 months for an initial contact @month end	266	386	546	369	1213	1207	1928	916	2364

Please also note that this is an interim dataset as we await the roll out of the National Information Management System and some individual CDNTs indicate that they do not have a system in place to capture this level of activity, therefore there are gaps in data returns for some of the CHO Areas.

Assessment of Need process is set out in the Disability Act, 2005.

The Assessment of Need process is set out in the Disability Act, 2005. The aim of an Assessment of Need under the Disability Act is to identify whether a person has a disability, the nature and extent of the disability, any health and education needs arising from that disability, as well as what services are required to meet those needs.

The Disability Act outlines the statutory timelines under which Assessments of Need under the Act must be completed. In summary, the assessment report must be completed within 6 months of the date the application was received. While the HSE endeavours to meet its legislative obligations under the Act, it has struggled to achieve compliance with these timeframes. At end of Quarter 3, 2024, 10.3% of assessments were completed within the timeframes set out in the Disability Act 2005 and accompanying Regulations.

The total number of applications 'overdue for completion' at end of Quarter 3, 2024, now stands at 12,722 (including 558 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) – which represents an increase of 30% on the end 2023 figure of 8,893. This is largely due to the following:

- A 25% increase in the number of applications for AON received in 2023 from 6,775 to 8,472. This growth has continued into 2024, with a further **7,852 received to end Quarter 3** (1,640 up on same period last year).
- A total of 3,205 AONs were completed in 2023. The percentage of these AONs that show 'No Disability' has increased significantly from 15.8% in 2010 to 27% in 2023. The significance of this is that the AO and possibly Assessors would have spent time assessing these applications as they would have either gone through the AON process and deemed not to have a disability (as defined by the Disability Act), or they would have begun the process and been identified as not having a disability during the desk-top phase. This trend has continued into 2024, with 32% of AONs indicating 'no disability'.
- The judgement in the case of CTM & JA v the HSE March 2022 found that the Preliminary Team Assessment (PTA) approach described in the HSE's SOP for Assessment of Need did not meet the requirements of the Disability Act. The HSE is now required to deliver diagnostic assessments where necessary and appropriate as part of the AON.
- The number of applications for AON under the Act has risen steadily since its implementation in June 2007, largely driven by the High Court ruling in 2009 which confirmed that eligibility for AON applies to persons born on or after 1st June 2002.
- The non-commencement of the Education for Persons with Special Education Needs (EPSEN) Act (2004). 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 2023, this figure averaged 62%. To date in 2024, this figure has increased to 64%. This is a reflection that the AON process is an accumulative process in terms of numbers of children and young people seeking access.

Please see the table below which gives the number of AON applications overdue at the end of Q3 2024 as extracted from the AOS (AON information management system).

СНО	Overdue	<1 month	1 - 3 Months	>3 Months
AREA 1	539	66	68	405
AREA 2	308	41	60	207
AREA 3	396	17	25	354
AREA 4	932	91	172	669
AREA 5	567	40	66	461
AREA 6	1252	125	235	892
AREA 7	4205	126	384	3695
AREA 8	1451	150	293	1008
AREA 9	3072	146	297	2629
Total	12722	802	1600	10320

Table 1: Applications overdue for completion end of Quarter 3, 2024

To date in 2024, 2,888 AONs have been completed, which is a 24% increase on the same period last year. This increase is due in part to the new targeted waiting list initiative that commenced end of May 2024, where the Government allocated funding of \in 6.89 million to facilitate the HSE to procure up to 2,500 additional AONs, with delivery targeted over the next 6 months. This funding is in addition to existing HSE core funding of the \in 5m, allocated for procurement of private assessments.

This waiting list initiative will target those families waiting longest for AONs, with the HSE reimbursing clinicians directly through the procurement of capacity from approved private providers. This provides a more equitable and fair approach rather than reimbursement of parents directly. It is envisaged that this initiative will be progressed through the existing framework of providers procured by each CHO Area, while also seeking to expand the list with any new private provision.

Information received from the CHO Areas indicates that under this targeted initiative, 1,410 AONs have been commissioned from private providers/assessors during June, July, August and September at a cost of €4,655,182. This suggests that the average cost per AON is €3,300.

	Number of AONs	Cost	Average Cost per AON
June	379	€1,245,455	€3,300
July	342	€1,155,703	€3,379
August	371	€1,173,031	€3,162
September	318	€1,080,993	€3,399
Total to date	1,410	€4,655,182	€3,302

However, despite this increased activity in relation to AON, waiting lists are growing as demand outstrips system capacity. In this regard, we anticipate that, by the end of 2024, there will be over 17,472 AONs due for completion, comprising: AONs overdue at end of Q3 2024 (12,722); AONs expected during the remainder of 2024 (2,250); as well as 2,500 Preliminary Team Assessments carried out under the previous Standard Operating Procedure (SOP), an approach found by the High Court not to have met the requirements of the Disability Act.

The increased numbers of applications for Assessment of Need, which is a legal entitlement under the Disability Act 2005, is a reflection of the increase in population and of families exploring all options for accessing services for their child.

However, as outlined above, an AON is not required to access Primary Care, Children's Disability Services or Mental Health Services providing services including assessment, goals setting, intervention and follow up services. This direct access ensures more efficient and timely access for many families.

Yours Sincerely,

Bernard O'Regar

Bernard O'Regan Assistant National Director National Disability Team