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.

4th March 2025

Deputy Ivana Bacik,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: ivana.bacik@oireachtas.ie

Dear Deputy Bacik,

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: 9130/25

To ask the Minister for Children; Equality; Disability; Integration and Youth the number of children on CDNT waiting lists with a diagnosis or a query of foetal alcohol spectrum disorder in each of the past two years, in tabular form; and if she will make a statement on the matter

HSE Response

Foetal Alcohol Spectrum Disorders (FASD) is a group of disorders associated with a range of lifelong physical, mental, educational, social, and behavioural difficulties. They are caused by prenatal alcohol exposure. FASD is often an invisible disability, yet prenatal alcohol exposure is the leading preventable cause of neurodevelopmental disorder. The prevalence and epidemiology of FASD in Ireland is not known. An estimated 2.8 – 7.4% of the population of Ireland might have FASD, according to a 2017 systematic review.

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 or service required. Services are provided following individual assessment according to the person's individual requirements and care needs. Services provided are tailored to the individual needs and requirements of the child/adult with disabilities.

The role of the HSE is to provide a multi-disciplinary team approach which includes the provision of health and personal supports required by children with disabilities due to FASD and incorporates hospital/ acute services, primary care and community services.

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. Children may access supports from a Children's Disability Network Team or from Primary Care depending on the complexity of their needs.

Childrens Disability Services

In line with the Progressing Disability Services model, 93 CDNTs, aligned to 96 Community Healthcare Networks (CHNs) across the country, are providing services and supports for children aged from birth to 18 years of age.

Each CDNT covers a specific geographical area and holds a waiting list for children with complex needs residing in that 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 43,000 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 needs as a result of their disability.
- Growth in demand for Assessment of Need, diverting further resources away from interventions

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, has four Working Groups which report into a Service Improvement Programme Board every month which in turn reports to the Roadmap Oversight Group which was chaired by the Minister of State

Working Group 1 **Integrated Children's Services** – has responsibility for the implementation of National Access Policy (NAP) and the Primary Care, Disability, CAMHS Joint Working Protocol (JWP), Equity of Access to Aids and Appliances across all CHOs; and the Review of HSE Tusla Joint Protocol.

Working Group 2*:* **Service Access and Improvement** – has responsibility for Waitlist Management and Services; Optimising Teams Efficiencies, Effectiveness and Governance; AONs overdue for completion; and the development of a National Capital plan to enable all staff of a CDNT to be co-located.

Working Group 3***:*** **Workforce** – has 21 actions dedicated to Retention of specialised CDNT staff, Recruitment of new graduates and experienced staff for all CDNTs Deployment of Students/Trainees/New Graduates; and Development of Existing Staff.

Working Group 4: **Communication and Engagement** – has responsibility for developing and ensuring the delivery of a rolling Communication Plan for the Roadmap and CDNT service, which is a key priority; review and updating the HSE PDS Website to meet information needs of families, further Staff Engagement and Workshop days and ensuring sustainability of the Family Forums and Family Representative Groups.

In addition, the Cross Sectoral Group on issues for children with disabilities will be resumed in the coming weeks to drive integration and collaboration between education and health services, and supports for special schools for optimal benefit and outcomes for children with disabilities.

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.

The CDNTIMS (information management system) has been rolled out across 50 CDNTs. There is an ongoing Legal issue for S38/S39 Lead Agencies however this is nearing resolution which will facilitate all remaining teams to migrate to the system in 2025.

Pending full roll-out, manual data collection is on-going. The table on the next page is the validated data for the end of December 2024 activity reports. This shows the number of children that are waiting for an initial contact with a CDNT in the 9 CHO Areas.

As mentioned earlier, 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. In that context, there are no waiting lists per type of disability or diagnosis.

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	109	175	247	157	82	61	151	296	48
No of children waiting 4-6 months for an initial contact @month end	70	102	157	120	83	74	153	178	62
No of children waiting 7-12 month for an initial contact @month end	58	136	298	104	150	138	325	282	128
No of children waiting over 12 months for an initial contact @month end	405	242	605	305	1091	1228	1942	800	2358

In addition, 722 children (&/or their parents) who are on the CDNT waiting list participated in one or more individual and/or group intervention appointments during December 2024.

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.

Further information regarding Foetal Alcohol Spectrum Disorders (FASD)

The HSE Alcohol Programme established a Foetal Alcohol Spectrum Disorders (FASD) Expert Advisory Group in September 2020, a multidisciplinary group, to support the HSE Alcohol Programme work on FASD prevention.

In 2022, it undertook a survey of Irish healthcare, social care, and education professionals' knowledge, attitudes and experience of FASD. Some of the findings indicated key needs such as a model of care, care pathway and need for training and support.

The HSE has developed a position paper on the prevention of FASD which outlines 14 key actions for the HSE to be achieved within the next 5 years. This includes the development of a model of care for FASD. This body of work is been led by HSE Health and Wellbeing Strategy & Research.

Further information can be found here:

https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/alcohol-programme/hse-position-on-prevention-of-fasd.pdf

In 2024, the HSE Alcohol Programme has lead on the development of the FASD learning module for healthcare staff. This need was identified through the survey of health care professionals in 2022. This is noted as action 11 on the HSE FASD Position Paper.

Further information regarding the HSE Alcohol programme can be obtained at:

https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/alcohol-programme/

Yours Sincerely,

Bernard O'Regan
Assistant National Director,
Access and Integration
Disability Services