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Deputy Verona Murphy
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Dear Deputy Murphy

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 13073/22

To ask the Minister for Health the number of children nationally under the age of 18 currently waiting to be seen by child disability and autism services; the length of time each child is on the wait list; and if he will make a statement on the matter.

HSE Response

Children who require a diagnostic assessment for ASD access these assessments through Children's Disability Network Teams (CDNTs). Child & Adolescent Mental Health Services (CAMHS) or through Primary Care depending on their presenting needs. The HSE does not provide services based on diagnosis and does not record waiting lists on this basis.

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, the remainder of 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.

These 91 Children's Disability Networks (CDN) are aligned to 96 Community Healthcare Networks (CHNs) across the country and each Children's Disability Network has one CDNT providing services and supports for children aged from birth to 18 years of age.

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.

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.

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.

Yours sincerely

Bernard O'Regan
Head of Operations - Disability Services,
Community Operations

