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17th May 2022

Deputy Mick Barry,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: mick.barry@oireachtas.ie

Dear Deputy Barry,

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: 22446/22

To ask the Minister for Health the number of children that are on the waiting list to access treatment for autism following diagnosis; and if he will make a statement on the matter.

HSE Response

Children's disability services are provided based on the presenting needs of the child rather than by their diagnosis or the actual type of disability or service required. Services are provided following individual assessment according to the child's individual requirements and support needs.

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.

Progressing Disability Services for Children & Young People (PDS)

The implementation of the Progressing Disability Services for Children & Young People (PDS) programme is agreed Government and HSE policy. This major reform programme 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. The first step in this programme was the reconfiguration of children's disability services into Children's Disability Network Teams to provide equitable access and child and family centred services based on need rather than diagnosis, and regardless of the nature of a child' disability, where they live or which school they attend. This policy aligns with the UN Convention on the Rights of People with Disabilities and also the objectives of Sláintecare and the Programme for Government 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.

The programme 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 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 rather than based on diagnosis. 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):

All 91 Children's Disability Network Teams are now in place. These teams provide services and supports for all children with complex needs within a defined geographic area.

CDNTs are teams of health and social care professionals (e.g., occupational therapists, psychologists, physiotherapists, speech and language therapists, social workers) and others disciplines (e.g., nursing). The reconfiguration into CDNTs and the resultant staffing mix was influenced by a number of factors including the staff resources of existing services and the available skill mix. Hence, some CDNTs may include disciplines such as nurses, family support workers or early educators.

Regardless of the nature of their disability, where they live, or the school they attend, every child with complex needs and their families have access to the full range of family centred services and supports of their 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 are provided as is feasible in the child's natural environments - their home, school and community.

Since 2019, more than 475 development posts have been allocated to children's disability services across the country. These posts have been assigned based on a number of factors, including the existing ratio of staff to the number of children with disabilities in each area.

Included in the 475 posts referenced above, the NSP 2022 provides for 190 therapy posts at a cost of €8.2m in 2022, increasing to €14.4m in 2023. This is a further substantial increase in the provision of funding in support of the development of the Children's Disability Network Teams, building on the 185 posts provided for in 2021.

The additional posts provided for under the National Service Plans for 2021 and 2022 are intended to support the newly established CDNTs to prioritise intervention for children with complex needs.

An extensive National Team Development Programme was developed and delivered online by the HSE in partnership with its Lead Agencies over 2020 – 2021 to prepare the 91 Children's Disability Network Managers and their staff for the establishment of their CDNTs and development of child and family centred services. In 2022, the HSE will provide an additional programme of support to all managers and their teams on strengthening their family centred practices to ensure that services and supports provided are based on priorities identified by the each family specific to their child.

Work is ongoing on mapping specialised services and supports, and paediatric supports available and gap analysis for children with highly complex needs, in order to develop standardised approaches to integrated pathways of support for CDNTs and Primary Care staff.

The HSE acknowledges that the transition to CDNT services has been challenging in some areas and that this has been stressful for children with disabilities and their families. The HSE is committed to working with the Department of Health, the Department of Children, Equality, Disability, Integration & Youth, the Minister of State for Disabilities and all key stakeholders to address particular areas of concern.

National Information Management System for the CDNTs (CDNTIMS)

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.

Autism Service Improvement Programme

Following the commissioning and publication of the *Review of the Irish Health Services for Individuals with Autism Spectrum Disorder* (the Review), the HSE commenced implementation of a Service Improvement Programme for the Autistic Community based on the recommendations of the Review.

National Autism Programme Board

A National Autism Programme Board was established with the responsibility for leading the implementation of the Review report recommendations. The Board consists of senior operational and clinical decision makers as well as independent professional / academic support.

Importantly, the Programme Board has representation of persons with lived experience of Autism participating as equal members of this collaborative team effort.

Implementation Priorities and Health Service Developments

In implementing the recommendations of the Review Report, the Programme Board has been tasked with leading out on an agreed set of priorities that will have greatest impact in terms of shaping how services can be delivered to people with Autism and in respect of creating greater awareness of Autism in terms of supporting communities in promoting inclusion and fostering positive attitudes.

The agreed set of priorities are summarised as follows;

i. Implement a Programme of Awareness Raising / Engagement with the Public;

ii. Build professional capacity and competence amongst key professionals working with Autistic people, including the implementation of a tiered model of assessment as recommended in the ASD Review Report.

Awareness Working Group:

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 has 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:
    - Location and types of services,
    - Tools and resources for service users, their families and clinicians and
    - 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.

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.

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. The draft protocol is being piloted initially in four Community Healthcare Organisations. It will then be evaluated to inform the further iteration and development.

Yours Sincerely,

Bernard O' Regan

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