



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

Office of the Head of Operations,
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10th June 2022

Deputy Dessie Ellis,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: dessie.ellis@oireachtas.ie

Dear Deputy Ellis,

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: 27928/22

To ask the Minister for Health the number of children aged 3 to 5 years of age that were diagnosed with autism from 2018 to date in tabular form; and if he will make a statement on the matter.

PQ: 27929/22

To ask the Minister for Health the number of children aged 6 to 8 years of age that were diagnosed with autism from 2018 to date in tabular form; and if he will make a statement on the matter.

PQ: 27930/22

To ask the Minister for Health the number of children aged 9 to 12 years of age that were diagnosed with autism from 2018 to date in tabular form; 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. Care and/or services provided are tailored to the individual needs and requirements of the child/adult with Autism.

The HSE does not gather information routinely on the basis of diagnosis. So, while we know from previous studies that approximately 70% of those with Severe /Profound Intellectual Disability will also have Autism, although many will not have been formally diagnosed, there is no specific autism register in Ireland and the HSE is not currently able to provide detailed information on the number and age range of children diagnosed with autism.

Progressing Disability Services for Children & Young People (PDS)



The implementation of the 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 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 line with the PDS model, resources assigned to children's disability services are allocated to the 0 – 18 Children's Disability Network Teams (CDNTs).

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. Early Intervention Teams and School Age Teams previously in place have reconfigured into 0-18 CDNTs. Every child across the country with complex needs arising from their disability now has access to a Children's Disability Network Team.

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 works closely together in a family centred model, focusing on the child's and family's own priorities. Every child with complex needs has access to a team, regardless of the nature of their disability, where they live, or the school they attend.

Children and their families 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.

ASD Service Improvement Board



Other service improvements for people with autism include the establishment of the ASD Service Improvement Board.

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

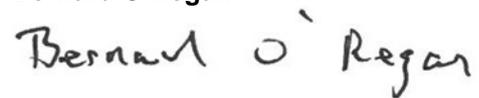


resources for service users, their families and clinicians and c) signposting to other essential community, voluntary and statutory based supports and services.

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

Yours Sincerely,

Bernard O'Regan

A handwritten signature in black ink that reads "Bernard O'Regan". The signature is written in a cursive style with a clear 'O' and 'R'.

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

