



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

Office of the Head of Operations,
Disability Services/Social Care Division,
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13th September 2023

Deputy Darren O'Rourke,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: darren.orourke@oireachtas.ie

Dear Deputy O'Rourke,

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: 38440/23

To ask the Minister for Children; Equality; Disability; Integration and Youth the number of children aged between 0-8 years old who were diagnosed with autism in 2022 and to date in 2023, in tabular form.

HSE Response

The Health Service Executive does not currently collect information specifically on adults and children identified with Autism on a national basis.

Children who may present with an Autistic Spectrum Disorder can present either through; Primary Care Services, through Children's Disability Network Teams (CDNTs), through Child and Adolescent Mental Health Services (CAMHS), or through the Assessment of Need process under the Disability Act, 2005.

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 principle and importance of early intervention is recognised by the HSE across its services and in particular in the context of the services and supports it provides to children with disabilities, and their families. Additionally, in developing the national policy for the provision of children's disability services, the focus of the HSE is to ensure that services are:

- Reflective of best national and international practice
- Responsive to the requirements of the UN Convention on the Rights of Persons with Disabilities
- Family and child centred
- Provided as close as possible to the community where children and their families live in line with Sláintecare.



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, access to children's disability services has changed 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 or where they go to school.

PDS is a significant change programme for the provision of services and supports for children from birth to 18 years of age, 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 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 with ASD may access supports from a Children's Disability Network Team or from Primary Care depending on the complexity of their needs.

Children's Disability Network Teams (CDNTs)

There are ninety one Children's Disability Network Teams (CDNTs) providing services for children with complex disability needs aged 0 – 18 years.

Regardless of the nature of their disability, where they live, or the school they attend, every child with complex needs including autism 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.

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.

Autism Service Improvement Programme

In addition, there are ongoing improvements in the provisions of services for children and adults with autism.

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 important collaborative team effort.

The Service Improvement Programme

Following the commissioning and publication of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorder (the Review) in November, 2017, the HSE initiated a Service Improvement Programme for the Autistic Community comprising of a number of Service Improvement Projects. The Programme aims to respond to the need for greater awareness amongst clinicians and the general public regarding both the autistic community and the support for Service Providers working with people with autism.

This programme was subsequently renamed to The Service Improvement Programme (SIP) for the Autistic Community, due to use of language and that we should refer to autistic people.

The Service Improvement Programme for the Autistic Community work streams are as follows:

1. The identification of a Standardised Assessment/Pathway 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.
 - The pilot protocol has been developed and has been operational in CHO 2 and CHO 9 since April 2022. Following an initial review of progress in September 2022, the protocol has been further refined and is currently being extended to additional Community Health Networks in CHO 2 and CHO 9, and to two new CHO's, CHO 4 and CHO 7, commencing late Q3 2023.
2. Building Awareness of the autistic community and the services and supports available to those with autism, both within the Service User, Family Member and Carer communities, and within the Service Providers themselves.
 - The content pages for the website has been developed and reviewed by the Subject Matter Expert's (SMEs), this is progressing to user testing phase in early Q3.
 - Phase 1 of the work on the development of a national service directory is completed, with the inclusion of all HSE delivered services into the directory. Phase 2 will commence in Q4 to capture all HSE funded voluntary sector services for inclusion in the directory.
 - On completion of user and accessibility testing, the directory and content will go live on the new HSE autism information website.

Autism Information Line

The HSE funds AsIAM to provide a phone line for the autistic community for a three year period.

With HSE support, AsIAM operates the Information Line by phone and instant messaging for not less than 20 hours per week (presently 5 hours a day, 4 days per week) with email support provided Monday-Friday.

The calls will be responded to by either a clinician or an appropriately qualified autistic advisor to ensure appropriate responses and supports to meet the needed and concerns of the range of callers and to inform follow-on activity.

The aim of the service over the next three years will be to develop the range of information resources, seminars and programmatic activity so that callers will receive the information and support they need.

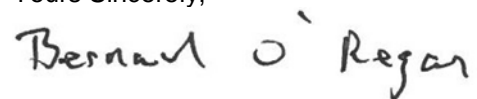


The service will operate within the “Partnership for Change” model, building on the capacity of individuals and families to manage the challenges of everyday life. All callers will receive a follow-on email summarising their call and where required, providing follow-on information and tools.

The service will be widely promoted nationally through a co-branded information campaign and will operate on both a phone line and instant messaging basis.

Annual insight reports, in addition to interval data reports, on calls received and topics explored, will be provided to inform HSE and government policy in the area of autism.

Yours Sincerely,

A handwritten signature in black ink that reads "Bernard O'Regan". The signature is written in a cursive, slightly slanted style.

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

