



Oifig an Cheannaire Oibríochtaí,
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
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4th October 2023

Deputy Michael Healy-Rae,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: michael.healyrae@oireachtas.ie

Dear Deputy Healy- Rae,

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: 39593/23

To ask the Minister for Children; Equality; Disability; Integration and Youth the reason for the increased number of children diagnosed with psychological conditions (details supplied); and if he will make a statement on the matter.

Details Supplied: Minister during the course of my constituency works I am extremely alarmed at the amount of parents who have children who have the following type of conditions, being non-verbal, have ADHD and all other types of issues which are affecting our young children more than ever in a psychological way, more than any other physical issue. Could I respectfully ask that a special look into what is causing the increase in children that have been born with these difficulties. Our education providers will tell you that there is a special needs assistances who are doing great work but would also agree we should be looking into this cause

HSE Response

The HSE does not gather information routinely on the basis of diagnosis. There is no specific autism register in Ireland and the HSE is not currently able to provide detailed information on the number of children and adults with autism or ADHD.

Although the HSE has experienced an increased demand for assessment of Autism, we cannot be sure that this is a result of increased prevalence. It may be due to increased awareness of autism coupled with a recognition for the need for earlier interventions. In addition, many individuals with autism, due to the complexity of their presentation may have a primary diagnosis of intellectual disability or a co-morbid mental health component such as ADHD.

Studies have found that variations and changes in ASD prevalence rates reported may have several explanations: changes or broadening of the diagnostic criteria, differences in methods used to study prevalence (sampling procedures, application of statistical methods) as well as an increased awareness among parents, professionals and the general public.



Other reasons could include:

- Greater access to services
- COVID to an extent – there is an increase in reported child anxiety and school refusals
- Better diagnostic services

The Department of Health's (DoH) "Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population: A Review of Data sources and Epidemiological Studies" published in November 2018, finds that policy changes and associated legislation have in part contributed to the reported increase in prevalence of ASD globally and that a similar trend has occurred in Ireland.

This report also states that there is currently no reliable method of estimating prevalence of Autism Spectrum Disorder in Ireland and a combination of methods was used in the report to arrive at a figure which may be used for assessing need and planning appropriate services.

Several commissioned reports in Ireland over the past number of years have resulted in greater parental and professional awareness of ASD. The DoH's report stresses that it is important to agree a national prevalence rate in order to plan services (social, educational, health) for this group of individuals. The Department of Education has used a prevalence rate of 1.5% based on the number of children with a diagnosis of ASD who are currently accessing special education services. This is a rational approach and it is similar to international rates.

An extremely wide range of individual differences is represented within the Autistic Spectrum Disorder categorization, from individuals who also have a severe learning disability to those with average and above average intelligence. All share the triad of difficulties in reciprocal social interaction, communication, and a lack of flexible thinking. ASDs impact on all areas of functioning and have enormous implications throughout the lives of those affected across the entire ability range. It is important that an accurate method of determining prevalence of ASDs is agreed, and that the prevalence rate is kept under review.

This report can be found at the following:

<https://health.gov.ie/wp-content/uploads/2018/12/ASD-Report-Final-19112018-For-publication.pdf>

Progress regarding establishing a reliable method of estimating prevalence of Autism Spectrum Disorder may be challenging. Different clinicians appear to have different thresholds when interpreting whether someone is or is not on the ASD spectrum / continuum (as is reflected in different data sources).

Childrens Disability Services

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 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

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

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.

Service Provision

The CDNTs are currently providing services and supports for 45,741 children and strategies and supports for urgent cases on the waitlist where staffing resources allow.

Children with complex needs and their families are offered evidence informed universal strategies and targeted supports based on individual needs and available staffing resources as part of their therapeutic programme. In addition, they may need individual one to one interventions at different stages of their development based on individual and emerging needs.

CDNTs, in line with national PDS policy, offers services based on the child's individual needs and family priorities as identified in the child's Individual Family Service Plan (IFSP) through a family centre practice model.

This model of service ensures that the supports provided are determined from family priorities, taking into account the factors relevant to each child. It recognises that each family has its own role, values, structures, beliefs and coping styles and it aims to strengthen families own abilities in dealing with their child's challenges. This approach is supported by national and international best practice.

It is important to note that the establishment of the CDNTs has removed the previous postcode lottery resulting from historical inequitable service development and local service provider barriers to access.

Specific Autism Supports and Services

The HSE funds specialist disability services for people with a disability including adults and children with intellectual disabilities, as well as to service users with physical, sensory or neurological disabilities, or autism.



Disability Services provided throughout the country, include Residential, Day and Respite Services; Home Support & Personal Assistant Services; Children's Services and Multidisciplinary supports for children and adults, including persons with ASD.

As mentioned above, many individuals with autism due to the complexity of their presentation may have a primary diagnosis of intellectual disability or a co-morbid mental health component. In this context, it is important to note that the provision of supports and services cross a range of services.

A number of service improvements are being introduced that, when implemented, will help improve access to services for people with autism.

This work takes two specific forms, a Task Group established under the National Clinical Programme for People with Disability to design improvements in adult disability services generally; and more specifically related to autism, a Service Improvement Programme for the Autistic Community has been commenced.

Access to CAMHS for individuals with dual diagnosis

In 2017, the HSE CAMHS, Disabilities and Primary Care National Working Group was convened to address service gaps for children with a disability and other comorbidities. The output of the work was the nationally approved *Joint Working Protocol for Primary Care, Disability and Child and Adolescent Mental Health Services*. This was informed by case studies, identifying existing service pathways and silos for children with complex needs including disabilities and mental health, and developing integrated pathways, governance and structures for children and families whose needs cross between Primary Care, Disability Services and CAMHS.


The Protocol builds on the *Integrated Children's Services Forum* (ICSF) to be established in each area under the National Access Policy. This is to provide a formal, regular mechanism for services to meet and discuss individual children whose needs are not clear or who may require some level of joint assessment and/or intervention and for whom direct consultation between the relevant services has not led to a decision on the best arrangement for the child.

However, to date, there has been limited implementation of the Joint Protocol and poor progress on joint working and developing the principle of 'team around the child' rather than children circling teams trying to find a pathway into services. Disability Services often find that CAMHS automatically refer autistic children to CDNTs, who do not have competencies to support their mental health needs.

The CDNT Roadmap for Service Improvement establishes a clear, robust governance structure at national level to drive the delivery of integrated services between Disabilities, Primary Care, CAMHS and Tusla at local level, providing the critical building blocks for service integration for the benefit of children and families. Fundamental to this is the implementation of the Primary Care, Disabilities, CAMHS Joint Protocol and National Access Policy by Primary Care, Disabilities and CAMHS jointly for all children with disabilities.

In this context, the National Director of Community Operations has commenced engagement with Chief Officers regarding Children's Integrated Services.

Yours Sincerely,



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

