Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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27th October 2021

Deputy Colm Burke,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
e-mail: colm.burke@oireachtas.ie

Dear Deputy Burke,

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 51315/21

To ask the Minister for Health the way information is gathered on the number of persons diagnosed with autism spectrum disorder; if the numbers of persons diagnosed with autism spectrum disorder are collated; and if he will make a statement on the matter.

PQ 51316/21

To ask the Minister for Health her plans to establish a specific autism register in Ireland; and if he will make a statement on the matter.

PQ 51317/21

To ask the Minister for Health his plans to establish public assessment teams dedicated to adult diagnoses of autistic spectrum disorders; and if he will make a statement on the matter.

PQ 51320/21

To ask the Minister for Health the most reliable autism diagnosis data health services use; the number of adults and children that have received a diagnosis; and if he will make a statement on the matter.

PQ 51318/21

To ask the Minister for Health the position regarding the Progressing Disability Services for Children & Young People and local Implementation groups that are overseeing the provision of services regionally; and if he will make a statement on the matter.

PQ 51319/21

To ask the Minister for Health the number of children's disability network teams that have been established nationwide; when it is envisaged there will be full national cover; and if he will make a statement on the matter.

HSE Response

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 or service required. Services are provided following individual assessment according to the person's individual requirements and care needs. Care and/or services provided are tailored to the individual needs and requirements of the child/adult with ASD.

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 of children and adults with autism.

Prevalence of Autism

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.

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.

The Department of Health's "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

Progressing Disability Services for Children & Young People

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. The PDS programme will ensure that services are provided for children with complex needs regardless of where they live or where they go to school. Each Community Healthcare Organisation will work with key stakeholders in their area including parents and education services to ensure that appropriate arrangements are put in place to facilitate in-reach services to special school settings as appropriate.

The Progressing Disability Services for Children and Young People (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.

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 and adults with a disability who have support needs can be effectively supported within mainstream child and adult health services. This policy will provide 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).

The HSE is committed to the full implementation of the Progressing Disability Services for Children and Young People Programme (PDS). 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.

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) rather than to a dedicated early intervention team or dedicated school age team.

91 Children's Disability Networks (CDN) are aligning to 96 Community Healthcare Networks (CHNs) across the country and each Children's Disability Network will have one CDNT providing services and supports for children aged from birth to 18 years of age. Early Intervention Teams and School Age Teams already in place are reconfiguring into 0-18 CDNTs. On full reconfiguration of children's disability services into CDNTs, every child across the country with complex needs arising from their disability will have 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. Once all teams are in place, 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.

The first step for all areas is the reconfiguration of existing staff resources into CDNTs. The staffing mix available in each area will be influenced by the historical development of services. For example, some areas may have a significant number of nurses available for reconfiguration, others may have family support workers or early educators.

Since 2019, 285 development posts have been allocated to children's disability services across the country. This includes 100 posts allocated under the HSE National Service Plan 2021. 185 development posts were allocated to children's disability services across the country in 2021. 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.

In June 2021, the Minister of State for Disabilities confirmed that the HSE should progress the recruitment of 85 whole time equivalent (wte) posts to facilitate the provision of in-reach services to those special schools that have heretofore provided a school based service. These staff members will be employed as part of the new CDNTs and will report to the Children's Disability Network Manager. CHOs must ensure that the allocation of any posts to CDNTs are targeted towards providing appropriate interventions.

Services in most parts of the country have now reconfigured to CDNTs. The remaining teams will be established before the end of 2021, thereby all 91 CDNTs will be in place and delivering services at that time.

Please see the table below which outlines the current status of the CDNTs in each of the nine Community Healthcare areas.

CHO	Status
1	7 CDNTs in place since 20/9/21
2	6 CDNTs in place since 11/10/21 3 CDNTs in mayo to be established in Dec '21
3	7 CDNTs in place
4	14 CDNTs in place
5	12 CDNTs in place since 27/9/21
6	7 CDNTs in place since 13/9/21
7	11 CDNTs in place since 20/9/21
8	12 CDNTs to be established Meath / Louth from 25/10/21 Midlands from 29/11/21
9	12 CDNTs in place since 20/9/21

Yours sincerely,

Bernard O' Regan

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