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19th July 2022

Deputy Ivana Bacik
Dail Eireann,
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Dublin 2.
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Dear Deputy Bacik

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 36228/22

To ask the Minister for Health if he intends to develop further services to address the needs of children and adults with autism; and if the implementation of such services will be informed by feedback from members of the autism community.

PQ 36218/22

To ask the Minister for Health if he intends to compile updated data on the prevalence of autism in Ireland

PQ 36227/22

To ask the Minister for Health if he intends to introduce new guidance for health service providers on the way to meet the needs of persons with autism and their families and carers.

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.

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

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).

However, a number of service improvements are being introduced that, when implemented, will help improve access to services for children with disabilities, including autism and developmental delays.

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 2021, In line with the PDS model, the remainder of ninety-one multidisciplinary CDNTs were established to provide services and supports for all children with complex needs within a defined geographic area.

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.

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.

A comprehensive PDS national team development programme has been provided for CDNMs and cascaded to all team members. This programme, which was designed to support the establishment of the new CDNTs and to support the implementation of the new model of service.

In addition to the above, a Service Improvement Programme for Autistic Community has been commenced. This has two work streams: Awareness Working Group and Assessment and Pathway Working Group

National Autism Programme Board:

The Service Improvement Programme (SIP) 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.

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;

1. Implement a Programme of Awareness Raising / Engagement with the Public;
2. 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:

The Awareness Stream of the programme aims to build Awareness of Autism, and the services and supports available to autistic people, both within the Service User, Family Member and Carer communities and within the Service Providers themselves.

It is designed to respond to the call for greater clarity amongst clinicians and Service Providers regarding both Autism and the supports available to autistic people by firstly developing a programme of better information for autistic people and their families, helping them to find services, access support and understand their condition better and secondly providing guidance to clinicians and service providers.

These objectives will be achieved by:

- Mapping and gathering information and resources relating to Autism by reviewing both national and international practices – 25% complete and work ongoing
- Review material available to provide information on services and supports. – 30% complete and work ongoing
- To explore gaps within resources available
- To engage with key stakeholders on the final set of information products and communication means. This will align with the standardised pathways which the Assessment and Pathways are working group to see section 2 hereunder
- To generate content for an online and print resource emerging from the above –
- To launch and promote the new information products.

Unfortunately, the Awareness stream of the project was vastly impacted and paused due to the Covid-19 Pandemic and the responses required of the Health Service. The project has recommenced and work will continue to be progressed in Q3 and Q4 2022.

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 offered across those providing services to people with Autism.

An interdisciplinary working group with lived experience representation was established and over 12 months period they developed a protocol to streamline autism assessment and intervention and match these to the complexity of presentation. The piloting of this protocol has now commenced. The tender for the independent evaluation of the Autism Assessments & Interventions Pathway Protocol was awarded to the Centre for Effective Services in December 2021, the service contract began in January 2022.

To assist the pilot phase an Expert Advisory Group (EAG) has been formed to provide oversight and advisory to the external independent evaluators Centre for Effective Services. The EAG comprises of one member with a clinical background, one member with lived experience and one member providing advisory relating to research, academic and ethical matters.

The participating pilot sites are within CHO 2, CHO 7 and CHO 9. The fourth pilot site envisaged to participate at tender stage (CHO 4) were unable to proceed due to a number of changes and challenges within their CHO at the time of commencement.

The pilot commenced over the three sites in February 2022, this involved engagement on the co-design and development of a tracker tool to track and assess the data throughout the pilot. The tracking and evaluation of the protocol is currently in progress and will run for a three month period. Fieldwork and interviews with service users and service providers will take place throughout July and August as part of the overall evaluation.

To date, there has been 22 service users assessed or have assessments scheduled in the coming weeks, this figure is expected to increase monthly.

The first stage of the pilot and evaluation will run up to September 2022 with an initial report due in October 2022. The second stage of evaluation will run to the end of March 2023, with the final report due by 24th May, 2023. The budget for stage two of the evaluation has been approved and we are currently engaging with HSE Procurement for re-tendering of the second stage of evaluation.

Yours sincerely

Mr Brian J Higgins,
Assistant National Director
Change Planning and Delivery – Disability and Mental Health Services