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13th September 2023

Deputy John Lahart,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: john.lahart@oireachtas.ie

Dear Deputy Lahart,

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: 37378/23

To ask the Minister for Children; Equality; Disability; Integration and Youth if he will report on any research that is or has been or continues to be undertaken in relation to the rising incidence of autism both at home and internationally (details supplied); and if he will make a statement on the matter.

Details Supplied: figures furnished by a constituent suggest that the ratio of children with Autism to those without appears to be escalating.

HSE Response

Autism

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.

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 (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).

However, a number of service improvements are being introduced that, when implemented, will help improve access to services 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.

Autism Service Improvement

Following the commissioning and publication of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorder (the Review), the HSE commenced implementation of a Service Improvement Programme for the Autistic Community based on the recommendations of the Review. This work takes two specific forms. First, a Task Group has been established under the National Clinical Programme for People with Disability to design improvements in disability services generally. This group is a multi-stakeholder group with lived experience representation. Secondly, and more specifically related to autism, a Service Improvement Programme for the Autistic Community has been commenced.

Service Improvement Programme for the Autistic Community

The Service Improvement Programme (SIP) was established with 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 programme aims to respond to the need for



greater awareness amongst clinicians and the general public regarding both autism and the support for Service Providers working with autistic people.

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 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 are achieved by:

- Mapping and gathering information and resources relating to Autism by reviewing both national and international practices
- Reviewing material available to provide information on services and supports.
- Exploring gaps within resources available;
- Engaging 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 Group are working to.
- Generating content for an online and print resource emerging from the above;
- Launching and promoting the new information products.

The Awareness Stream of the project had been significantly impacted and paused due to the Covid-19 Pandemic and the responses required of the Health Service. The project has recommenced at pace and work will continue to be completed in 2023.

In tandem with the above, the HSE agreed to fund AsIAM to provide a phone line for the autistic community for a three-year period.

AsIAM Phone Line for the Autistic Community

With HSE support, AsIAM intends to operate the Information Line by phone and instant messaging for not less than 20 hours per week (presently 5 hours per day, 4 days per week) with email support provided Monday to Friday. The calls are responded to by either a clinician or an appropriately qualified autistic advisor to ensure appropriate responses and supports to meet the needs 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, will be provided with follow-on information and supporting methods/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.

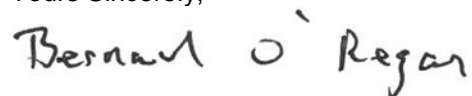
AsIAm was funded € 204,500 by the HSE, under a S39 Grant Aid agreement in 2022, and will continue to be funded in 2023.

Assessment and Pathway Working Group:

An interdisciplinary Assessment and Pathways Working Group has been working 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 works to agree a standardised service user journey and the implementation of a consistent core service offered across those providing services to people with Autism. The piloting of this protocol has now commenced across CHO's 2, 4, 7 and 9.

To assist the pilot phase, an Expert Advisory Group (EAG) has been formed to provide oversight and advisory to the external independent evaluators, the 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.

Yours Sincerely,



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

