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17th April 2023

Deputy Cian O'Callaghan,
Dail Eireann,
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Dublin 2.
E-mail: cian.ocallaghan@oireachtas.ie

Dear Deputy O'Callaghan, get reviewed by

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: 14673/23

To ask the Minister for Children; Equality; Disability; Integration and Youth the pathways that are in place for adults to access an assessment for autism spectrum disorder through the HSE; his plans to increase capacity for adults seeking an ASD assessment through the HSE; 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. Services are provided following individual assessment according to the person's individual requirements and service needs.

Based on presentation to the GP, individuals can be referred on to adult psychology in Primary Care or the Multidisciplinary Adult Disability Team.

It is acknowledged however, that the current system is very variable across the country and does not adequately serve the needs of adults with autism. In many areas adult assessments are only available privately, this is an unsatisfactory situation and we are working to address this. This work takes two specific forms. Firstly, there has been a Task Group 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.

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.

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;

- i.* Implement a Programme of Awareness Raising / Engagement with the Public;
- ii.* 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:

Information available to the Autistic community, Family Members, Carers and Service providers was limited and inconsistent from region to region and did not always reflect current understanding and approaches. The HSE, through the work of the Awareness Working Group have taken a comprehensive approach to addressing this, and is reviewing existing content, seeking the views of the Autistic Community, Family Members, Carers and Service Providers on this content, and working to ensure it can be produced and made accessible to people all over the country, online and in print. This quality process has been progressing and will continue into next year.

The Awareness Stream of the programme is designed to respond to the call for greater clarity amongst Clinicians and Service Providers regarding both Autism and the supports available to people with Autism.

There are a number of individuals with the lived experience participating in this group.

- The availability of comprehensive accessible information relating to Autistic people, their families, and healthcare workers working in the field
- The development of an online knowledge hub combined with a helpline aimed at providing contemporary information in relation to:
 - Location and types of services,
 - Tools and resources for service users, their families and clinicians and
 - Signposting to other essential community, voluntary and statutory based supports and services.

The outputs from this work will have wider application and benefits across all disability services.

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 offering across those providing services to people with Autism.

The Working Group, including people with lived experience of autism, will consult widely with key stakeholders in the design and formulation stage of the project; this is particularly important in the context of the implementation of a tiered approach to assessment. Its main work focus is to:

- Develop an operational model for a tiered approach to Autism Assessment through developing clear and functioning pathways to services.
- This will contribute to the NCPPD producing a Model of Service (including initial and ongoing assessment) for people with Autism, with appropriate sign off through the governance procedures of the NCPPD.
- An implementation plan to include training which takes cognisance of existing policies of the HSE
- Social Care/Primary Care/Mental Health Policy Training material to support the agreed approach to Autism Assessment.
- The development, where required, of processes or supporting protocols to underpin

The draft protocol is being piloted in two Community Healthcare Organisations, Community Healthcare West and CHO 9. Learning from the initial phase of the pilot is currently being considered with a plan to roll out.



Autism Information Line

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

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 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,



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

