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Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
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25th July 2022

Deputy Neasa Hourigan,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: neasa.hourigan@oireachtas.ie

Dear Deputy Hourigan,

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: 37554/22

To ask the Minister for Health the estimated cost to the Exchequer of setting up a pathway of diagnostic and after-care supports within the public health system for adults who wish to pursue an autism diagnosis; 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.

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. First, there has been a Task Group established under the National Clinical Programme for People with Disability to design improvements in adult 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

This programme was subsequently renamed to The Service Improvement Programme (SIP) for the Autistic Community, due to use of language and that we should refer to autistic people.

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. 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.

1. 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 Group are working to (please 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.

In tandem with the above 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

Supported by the HSE, the Information Line operates for 4 hours per day, five days a week. 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.

2. 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 a 12-month 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, and 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



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

