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9th September 2022

Deputy Violet Anne Wynne,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: violet-anne.wynne@oireachtas.ie

Dear Deputy Wynne,

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 43401/22

To ask the Minister for Health the services available for children who have ASD and who also have mental health difficulties.

HSE Response

The HSE acknowledges the challenges in meeting the demand for children's disability services and is acutely conscious of how this impacts on children and their families.

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 i.e. Primary Care for non-complex functional difficulties and Children's Disability Network Teams for complex functional difficulties.

Children's disability services are provided based on the presenting needs of the child rather than by their diagnosis or the actual type of disability or service required. Services are provided following individual assessment according to the child's individual requirements and support needs. Care and/or services provided are tailored to the individual needs and requirements of the child with ASD.

Children's Disability Network Teams (CDNTs)

In 2021, 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.

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.



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.

Based on presentation and assessment, children with disabilities who may also have additional health needs' requirements, are referred on to the appropriate service, including, if required, the local Child and Adult Mental Health Services (CAMHS).

CAMHS provide specialist mental health service to those aged up to 18 years, who have reached the threshold for a diagnosis of moderate to severe mental health disorder that require the input of multi-disciplinary mental health teams.

Community CAMHS refers to child and adolescent mental health services that are delivered in outpatient and day hospital settings, with the majority of CAMHS interventions being delivered in the community, close to people's homes. CAMHS community mental health teams (CMHTs) provide clinical assessment, formulation, diagnosis and multi-disciplinary interventions to children and adolescents based on their identified needs.

The HSE internal Joint Working Protocol Primary Care, Disability and CAMHS (2017) describes the processes for liaison and shared care when children require support from more than one service.

Autism Service Improvement Programme

There are ongoing improvements in the provisions of services for children and adults with autism.

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, 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

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, 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

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.

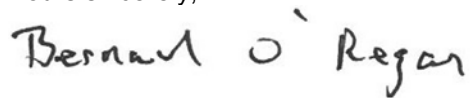
The participating pilot sites are within CHO 2, CHO 7 and CHO 9. The fourth pilot site envisaged to participate at tender stage (CHO 4) were unable to proceed due to a number of changes and challenges within their CHO at the time of commencement.

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