



Oifig an Cheannaire Oibríochtaí,
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
31-33 Sráid Chaitríona, Luimneach.

Office of the Head of Operations,
Disability Services/Social Care Division,
31-33 Catherine Street, Limerick.

T: 00353 (0) 61 483369
Suíomh Gréasáin/Website: <http://www.hse.ie>

19th October 2023

Deputy Claire Kerrane,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: claire.kerrane@oireachtas.ie

Dear Deputy Kerrane,

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: 43345/23

To ask the Minister for Children; Equality; Disability; Integration and Youth what services are available to young adults who require an assessment (details supplied) where the young adult can no longer access child and family psychology services; and if he will make a statement on the matter.

Details supplied: Requires assessment for Autism

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.



Specific Autism Supports and Services

The HSE funds specialist disability services for people with a disability including adults and children with intellectual disabilities, as well as to service users with physical, sensory or neurological disabilities, or autism.

Disability Services provided throughout the country, include Residential, Day and Respite Services; Home Support & Personal Assistant Services; Children's Services and Multidisciplinary supports for children and adults, including persons with ASD.

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. In this context, it is important to note that the provision of supports and services cross a range of services.

A number of service improvements are being introduced that, when implemented, will help improve access to services for people with autism.

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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.



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 the protocol will be in Community Healthcare 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.

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 initial phase of webpages relating to Autism content is available to the public on www.hse.ie – Phase 2 is due to commence in the coming month which includes a further 27 pages of autism related content, which is expected to be complete by Q3 2024. Work is ongoing in relation to the Service Directory.

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



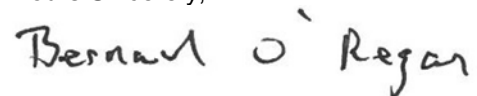
email summarising their call and where required, will be provided with follow-on information and supporting methods/tools.

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 is in receipt of € 250,000 in 2023.

Yours Sincerely,

A handwritten signature in black ink that reads "Bernard O'Regan". The signature is written in a cursive style with a clear, legible font.

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

