

National Director, Community Operations

Dr. Steevens Hospital, Dublin 8, DO8 W2A8 Tel: 01 6352596 Email: communityoperations@hse.ie

Stiúrthóir Náisiúnta, Oibríochtaí Pobail

Ospidéal Dr. Steevens' Baile Atha Cliath 8, DO8 W2A8 T 01 6352596 R: communityoperations@hse.ie

13th February 2024

Deputy Pauline Tully Dáil Eireann Leinster House Kildare Street Dublin 2.

PQ 57308/23 — To ask the Minister for Health if, in line with Action 95 of the Autism Committee's Final Report, he has plans to offer individual health plans to autistic people, including health check-ups, to ensure that they are supported in accessing health services; and the estimated first- and full-year cost, respectively, of implementing this proposal.

- Deputy Pauline Tully

Dear Deputy Tully,

The Health Service Executive (HSE) has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted to the Minister for response.

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.

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.

Service Improvement Programme for the Autistic Community

The HSE has commenced implementation of a Service Improvement Programme for the Autistic Community based on the recommendations of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorder and consists of senior strategic, operational and clinical decision makers, as well as independent professional /

academic support. Importantly, the Programme Board has the representation of persons with lived experience of Autism participating as equal members of this important collaborative team effort.

The Programme Board is 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 creating greater awareness of Autism through supporting communities to promote inclusion and foster positive attitudes.

The two primary priorities are (1) The implementation of a Programme of Awareness Raising and Communications, led by the Awareness and Communications Working Group and (2) The implementation of a tiered model of assessment as recommended in the ASD Review Report, led by the Assessment and Pathways Working Group.

Assessment and Pathways Working Group:

The Assessment and Pathways working group has developed 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 autistic people.

A demonstrator project commenced in 2022 to test the new assessment protocol. Two CHO areas participated in Phase 1 of the project (CHO 2 and CHO 9). Following the completion of Phase 1, CHO 9 have continued to use the Assessment Protocol for an "interim" phase, with over 120 assessments now completed using the protocol. Initial indications from Phase 1 show that the protocol is welcome and working both for service users and service providers. Phase 2 of the project commenced in September 2023 with 4 pilot sites participating (CHO 2, 4, 7 and 9).

Awareness and Communications Working Group:

The Awareness Stream of the programme aims to build Awareness of Autism, and the services and supports which are available to autistic people. It is designed to respond to the call for greater clarity amongst clinicians and Service Providers regarding information on autism and the supports available to autistic people.

Work in this area has progressed through two specific workstreams:

- (1) the development of a service directory of HSE direct services available to autistic people and their families across each CHO. Phase two of the directory development will include autism services provided by voluntary sector providers in each CHO.
- (2) The revision and redevelopment of the information on autism that is available to autistic people, their families and the public on the HSE website.

Phase one of the website redevelopment is complete and can be viewed on the HSE website for Autism. Phase two will commence in February 2024.

AsIAm

In addition to the above improvements, the HSE is providing funding to many organisations providing services to meet the needs and requirements of people with autism including AsIAm.

AsIAm (Autism Spectrum Information, Advice and Meeting Point CLG) was established in 2014 to support autistic people by providing information, advice and an online meeting point. AsIAm also provides a platform for autistic people to share their stories and views. A significant number of AsIAm employees are neurodiverse.

AsIAm undertakes a range of programmes and campaigns which work towards the goal of bringing about a more inclusive Ireland for those living with Autism.

AsIAm Phone Line for the Autistic Community

Since 2022, the HSE has funded AsIAm to provide a dedicated phone line for the autistic community.

With HSE support, AsIAm operates 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 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.

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.

Further information can be obtained at: https://asiam.ie/

I trust this information is of assistance to you.

Yours sincerely,

David Walsh

National Director

Community Operations