



**Oifig an Stiúirthóir Cúnta Náisiúnta,**  
Foireann Míchumais Náisiúnta,  
An Chéad Urlár - Oifigí 13, 14, 15,  
Áras Phlásóg na Rós, Coimpléasc Gnó na hOllscoile,  
Páirc Náisiúnta Teicneolaíochta,  
Caladh an Treoigh,  
Luimneach.

**Office of the Assistant National Director,**  
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7<sup>th</sup> August 2024

Deputy Ruairí Ó Murchú  
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Dear Deputy Ó Murchú,

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: 32360/24**

*To ask the Minister for Children; Equality; Disability; Integration and Youth his plans for assessing the best means of carrying out assessments of needs and therapies provision for those with autism; the interim services that will be made available while this assessment is being made; 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. Services provided are tailored to the individual needs and requirements of the child/adult with ASD.

With regard to children, 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 with ASD may access supports from a Children's Disability Network Team or from Primary Care depending on the complexity of their needs.

With regard to adults, based on presentation to the GP, individuals can be referred on to therapy services in Primary Care or the Multidisciplinary Adult Disability Team.

In addition, 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.



An extremely wide range of individual differences is represented within the Autistic Spectrum Disorder categorization, from individuals who also have a severe learning disability to those with average and above average intelligence. All share the triad of difficulties in reciprocal social interaction, communication, and a lack of flexible thinking. ASDs impact on all areas of functioning and have enormous implications throughout the lives of those affected across the entire ability range.

As a result, services provided, including therapy services, will be tailored to the individual needs of the person with ASD.

### **Childrens Disability Services**

93 Children's Disability Network Teams (CDNTs) are aligned to 96 Community Healthcare Networks (CHNs) across the country and are providing services, including therapy services and supports for children aged from birth to 18 years of age.

The model of service for all CDNTs is family-centred and based on the needs of the child. This includes universal, targeted and specialised supports and interventions, as appropriate to the individual child and family.

- The CDNTs are currently providing services and supports for 46,595 (End of June BIU metrics) children and strategies and supports for urgent cases on the waitlist where staffing resources allow. However, there are significant challenges for CDNTs including:
  - 
  - Significant staffing vacancies
  - Growth in numbers of children with complex need
  - Growth in demand for Assessment of Need, diverting further resources away from interventions.

The HSE's Roadmap for Service Improvement 2023 – 2026, Disability Services for Children and Young People is a targeted Service Improvement Programme to achieve a quality, accessible, equitable and timely service for all children with complex needs as a result of a disability and their families.

The Roadmap, now in implementation phase, contains 60 actions and include a robust suite of retention and recruitment actions to build existing CDNT service for all children with disabilities, including those with autism.

### **Targeted Initiative focussed on long waiting families**

With regard to an Assessment of Need under the Disability Act 2005, a new targeted waiting list initiative is in place and the Government has allocated funding of €6.89 million to facilitate the HSE to procure up to 2,500 additional Assessments of Need (AON) under the Disability Act 2005, with delivery targeted over the next 6 months.

This waiting list initiative will target those families waiting longest for AONs, with the HSE reimbursing clinicians directly through the procurement of capacity from approved private providers. This provides a more equitable and fair approach rather than reimbursement of parents directly.

It is envisaged that this initiative will be progressed through the existing framework of providers procured by each CHO Area, while also seeking to expand the list with any new private provision.

### **Service Improvements**

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 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.

#### **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 work streams:

- (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 at:

<https://www2.hse.ie/conditions/autism/>

#### **Development of the Autism Assessment and Intervention Protocol**

The Protocol has been developed through extensive consultation with people with lived experience of Autism and multidisciplinary input from the professions involved in autism assessment and interventions (services and supports to autistic people and their families).

The protocol facilitates practitioners to match the extent of assessment undertaken to the complexity of presentation of autism and possible co-occurring conditions. It recognises three Tiers of assessment (Tier 1: Autism Assessment; Tier 2: Autism Differential Assessment; Tier 3: Autism Extended Assessment) each allowing the clinician to determine the presence or absence of autistic traits or autism. The basis for moving through the different levels of assessment is where a clinician feels both uncertain about 1) the presence or absence of autistic traits or autism, and 2) unsure if any time of services or supports would be beneficial for the client.

Clinicians are guided by not restricted by suggested times for clinical assessment in each of these Tiers.

#### **Aligning Pathways to the Protocol**

Children, young people and adults should be able to access an assessment for autism at an early stage in their referral pathway. During the independent evaluation currently underway, important work is progressing on ensuring that service users can access an autism assessment, as close to their service access point as possible. We are also learning from



other models of services provision so that we can incorporate good practices into the final version of the protocol. We are aiming for this work to conclude the end of Q2.

## **Piloting**

The protocol has now been piloted across 4 CHOs during the last 18 months, which incorporated Phase 1, an Intermediate Phase and Phase 2. Phase 2 was complete at the end of Q1, 2024. Circa 200 service users participated in the piloting of the protocol, including children, adolescents and adults.

## **Independent Evaluation**

The Centre for Effective Services (CES) independently evaluated Phase one of the piloting and feedback from this was incorporated into Phase 2 of the piloting. The independent evaluation of the Intermediate Phase (when the protocol continued to be used as part of daily practice) and Phase 2 (when the use of the protocol was extended to other CHOs) is now beginning in Q2, 2024. This evaluation collects both quantitative data about the type of assessments conducted and the time to intervention, and qualitative data by interviewing both service users and services providers who have participated in the piloting. This in-depth and independent analysis is crucial to ensure that the needs of autistic people are being appropriately addressed by the new protocol. We expect a draft report for consultation with stakeholders around the end of Q3, 2024.

## **Roll Out**

Following a positive evaluation of the protocol and the incorporation of further learning from the evaluation, the protocol will proceed through a process across primary care, disability and mental health that will culminate in sign off by the HSE Clinical Forum before the end of Q1, 2025, when roll out across all 6 Regional Health Areas will begin. This will be accompanied by new training to enhance the awareness, knowledge and skills of staff working with autistic people.

An Autism Assessment training module will also be developed for HSE Land to strengthen and where appropriate broaden the pool of staff who are competent and confident to undertake assessments using the protocol. The development of this training will focus on each of the three levels of the protocol, beginning in the first instance with Tier 1 assessments.

## **AsIAM**

AsIAM (Autism Spectrum Information, Advice and Meeting Point CLG) was set up in 2014 to support people on the Autism Spectrum by providing information, advice and an online meeting point. AsIAM also provides a platform for people affected by Autism to share their stories and views.

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. These include:

- School staff training workshops for individual staff members on *Building Autism Understanding and Inclusion in Education*.
- Autism-Friendly Schools Portal
- Autism-Friendly Communities Portal
- Autism-Friendly Accreditation, which includes a “Charter of Inclusion” that sets out standards for supporting the autism community, and offers practical measures that organisations can put into place.
- A pop-up exhibition entitled “The Autism Experience” Exhibition, which has been supported by the Department of Justice & Equality, in venues across the country since June 2016, and aims to engage with all people, in gaining a greater insight into what it is like to live with Autism.
- The Teach Me AsIAM Early Years Programme, developed by AsIAM to provide an introduction to autism for professionals who work with young children (0-4 years.) The delivery of the programme has been divided into phases, with phase one delivered to early years educators and phase two delivered to early years support workers. This is to ensure consistency in the level of knowledge of autism across all professionals involved in



the supported development of young children. The programme is funded through Early Childhood Ireland's 'Pyjama Day' initiative.

- The AsIAM Autism University Award, which was awarded to Dublin City University (DCU) in 2018. DCU became the world's first autism friendly university through a collaboration between DCU, AsIAM and Specialisterne Ireland (a specialist consultancy that recruits and supports people with Autism).

Since 2018, AsIAM has been providing direct guidance and information to parents of children on the autism spectrum and autistic adults through a Community Support Team. This support was initially delivered by one member of staff, initially funded by philanthropy, but due to significant increases in demand this has grown to more staff members in recent years.

### **AsIAM Phone Line for the Autistic Community**

Since 2022, the HSE is funding AsIAM to provide a phone line for the autistic community for a three-year period.

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. 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 Augmentative and Alternative Communication Support Programme**

AsIAM will also receive funding to administer on behalf of the HSE, the Augmentative and Alternative Communication (AAC) Programme whereby Communication Devices will be provided to people with disabilities.

This programme is open to applications from Autistic children or adults who may benefit from a high-tech AAC device and associated support. The programme also aims to support the family and professionals supporting users to advance their knowledge and confidence in AAC.

The AAC support programme will run two separate referral processes

1. For Autistic children and families attending a speech and language therapist who will support the individual with device trial and set up.
2. For families/children not yet linked in with speech and language therapist.

The programme will:

- Support children's total communication by providing information and training to key stakeholders in the child's life, e.g., parents/carers and school staff on how to choose an appropriate AAC app through an AAC trial, introduce and model use of AAC.
- By providing individuals a communication device best suited to their individual needs that they can use with guidance from a Speech and Language Therapist to support their communication skills.

The AAC support programme aims to provide AAC/communication devices to the autistic community through two separate referral streams.

1. For individuals attending a speech and language therapist. Their speech and language therapist (SLT) will support the individual and their family through an AAC device trial to choose the communication device that best suits the individuals, and their families 'need. Their SLT will then apply to the AAC support Programme for an AAC device on their behalf, detailing how the AAC device trialled meets the individuals' needs and supports their communication.



2. For families/children not yet linked in with speech and language therapist, they will be provided with a device and supported through a trial of a communication app of their choosing. Parents will be supported through a series of online webinars and access to an SLT to troubleshoot any challenges that might arise.

In Stream 1, SLT's, individuals and families will be informed as to how to complete an AAC device trial and submit a device application to AslAm's AAC support programme. The person's assigned SLT will be responsible for supporting the person and their family in setting up and using their AAC device.

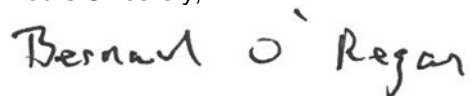
In Stream 2, children will be provided with a communication device and their parents/families will be supported through a trial of a communication app of their choosing. Service will be delivered via individual and peer group support sessions (guided by individual intake sessions). Level of intervention offered is education, consultation with SLT and peer support.

Aslam has received the first tranche of funding to progress the AAC programme.

The most recent update regarding the AAC programme is as follows:

- Recruitment for the appropriate personnel to manage the programme is currently concluding
- The procurement of devices, in line with OGP rules, is currently being finalised
- The programme manager is now in place and it is anticipated that we will begin to support families from September 2024.

Yours Sincerely,



**Bernard O'Regan**  
**Assistant National Director**  
**National Disability Team**

