

Oifig an Stiúrthóir Cúnta Náisiúnta,

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

Office of the Assistant National Director,

National Disability Team, First Floor- Offices 13, 14, 15, Roselawn House, University Business Complex, National Technology Park, Castletroy,

28th April 2025

Deputy Conor D McGuinness, Dail Eireann, Leinster House, Kildare Street, Dublin 2. E-mail: <u>conord.mcguinness@oireachtas.ie</u>

Dear Deputy McGuinness,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary questions, which were submitted to this department for response.

PQ: 15374/25

To ask the Minister for Health the plans to ensure that neurodivergent adults can access public healthcare no matter which county they are from and live in; and if she will make a statement on the matter

PQ: 15375/25

To ask the Minister for Health the plans to ensure that medical professionals receive an adequate amount of experience and training with neurodivergent persons; and if she will make a statement on the matter.

Response

Disability services focus on enabling people with disabilities to achieve their full potential, living ordinary lives in ordinary places, as independently as possible, while ensuring that the voices of service users and their families are heard, and that they are fully involved in planning and improving services to meet their needs.

The United Nations Convention on the Rights of Persons with Disabilities, or UN CRPD, is a human rights treaty developed by the United Nations. It outlines the rights of people with disabilities.

Ireland signed the UN CRPD in 2007, and ratified it in March 2018. Ratification of a human rights treaty can be thought of as a promise. It means that the government has promised to change laws, policies, and practices to make sure everyone can enjoy the rights set out in the treaty.

The implementation of the UN CRPD is monitored. In Ireland, it is monitored by the Irish Human Rights and Equality Commission, IHREC.

Article 25 of the UN CRPD concerns health: The right to the highest attainable standard of health. The right to receive health care, including specialised health care required because of a disability, without discrimination. The right to receive health care in one's own community, and to be treated with respect by medical staff and doctors, and have one's autonomy respected.

The HSE National Office for Human Rights and Equality Policy

This National Office aims to:

- Build skills, knowledge and confidence of staff
- Achieve HSE Compliance with Human Rights legislation
- Develop and promote HSE Human Rights and Equality Policy
- Influence legislative and organisational change to ensure that the human rights and dignity of each person using HSE services are respected.

One of the work streams of the office is Universal Access- Supports for people with Disabilities in the HSE under Part 3 Disability Act 2005.

The HSE appointed a National Specialist in Accessibility who provides guidance, advice and strategic support in the promotion of access for people with disabilities. The purpose of the role is also to develop a strategic framework for the implementation of Part 3 of the Disability Act 2005 in the HSE.

The Specialist will develop a plan to achieve compliance with Part 3 of the Disability Act, specifically in relation to actions 25-44 of the Department of Health and Children's Sectoral Plan. The post is based within the Advocacy Unit and works closely with the HSE National Disability Unit.

Please see:

https://www.hse.ie/eng/about/who/national-office-human-rights-equality-policy/universal-access/

Accessible Health and Social Care Services

The HSE has a network of access officers located throughout the country across community and acute services to support people with disabilities accessing health and social care services.

Contact details for access officers in the HSE can be found at <u>https://www.hse.ie/eng/services/yourhealthservice/access/accessofficers</u>.

To support the work of the Access Officers, the HSE published the *HSE National Guidelines for Accessible Health and Social Care Services*. These Guidelines offer practical guidance to access officers and staff about how they can provide accessible health and social care services. A review is currently underway of these Guidelines to ensure that they reflect the most up to date best practice and legislation with regard to supporting people with disabilities accessing health and social care service services, including neurodivergent adults. The current list of access officers will also be reviewed.

Once the updated guidelines and the review of access officers has been completed, the revised guidelines will be widely disseminated. Revised training will be provided to Access Officers which will include an emphasis on enhancing the skills and competencies of access officers in understanding the supports that neurodivergent adults may require when accessing health and social care services.

The HSE has also developed training on the Assisted Decision-Making (Capacity) Act 2015, which applies to all disabilities including neurodivergent adults. The two suites of e-learning is available to all staff in HSE and HSE funded services and covers the guiding principles of the Act, supporting decision-making, the functional assessment of capacity and advance healthcare directives. There is additional online and in-person training available for people who will be completing functional assessments of capacity under the Act. This training is complemented by a number of webinars on the Act which are available on www.assisteddecisionmaking.ie.

Advocacy Services

The role of advocacy is to support and enable people who have difficulty in exercising their rights, expressing their views, exploring options, and making informed choices.

An additional support and service for people who are neurodiverse include advocacy services such as the National Advocacy Services and SAGE.

The National Advocacy Service for People with Disabilities (NAS) continues to work on a range of issues, including housing, healthcare, and representation of individual preferences for people with disabilities.

Please see:

https://advocacy.ie/

In addition, the HSE funds several organisations providing advocacy services including Inclusion Ireland, Disability Federation of Ireland (DFI) and the National Federation of Voluntary Service Providers to ensure that the voices of people with disabilities are heard when it comes to changes in services and legislation that will improve the quality of life and participation of people with a disability in Irish Society.

DFI's stated vision is an Ireland where people with disabilities and disabling conditions are fully included and enabled to reach their full potential in the spirit of the United Nations Convention on the Rights of Persons with Disabilities, UN CRPD.

The Autism Innovation Strategy

On Monday, 26 August 2024, the Autism Innovation Strategy was launched by the National Disability Authority.

The Autism Innovation Strategy is the product of engagement with a range of Government Departments and statutory agencies to agree actions that will make a meaningful difference to the lives of autistic people within the 18-month time frame of the Strategy.

During the public consultation, prior to publication, health and social care, education, and autism training were the three areas that most respondents felt needed to be improved in the final Strategy

To promote improved understanding of autism across the public sector, the National Disability Authority supported by the Department of Children, Equality, Disability, Integration and Youth will introduce a new introductory e-learning module on disability equality. This will provide public sector employers and employees with the knowledge and skills to support autistic people and other people with disabilities in an effective, respectful and inclusive manner. This module will be co-designed with autistic people and other people with a disability and will be distributed widely across the public sector.

To promote neuro-affirmative models of practice by staff in the health and social care sector, the Strategy supports the development and promotion of an autism training framework for professionals working with autistic people in the Health Service Executive, in Section 38 and Section 39 organisations and in Tusla, Child and Family Agency.



The Autism Innovation Strategy can be accessed at:

https://www.gov.ie/en/department-of-children-equality-disability-integration-andyouth/publications/autism-innovation-strategy/

The HSE has a Knowledge Hub on HSeLanD for professionals. The Autism Masterclass HSeLanD module ID: 17600 is designed to equip healthcare professionals with evidence-based knowledge about autism, enhancing their ability to provide inclusive and effective care. Through a combination of knowledge-sharing and skill-building, attendees will be encouraged to reflect on and improve their practices to better support autistic individuals in a healthcare setting.

Service Improvement Programme

The Service Improvement Programme Board for the Autistic Community 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 autistic people. It is also tasked with creating greater awareness of autism in terms of supporting clinicians, other staff and local communities in promoting inclusion and fostering positive attitudes.

The Assessment and Pathways Working Group was established to develop a standardised assessment approach for use in all services dealing with the assessment of 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 people who are Autistic. The Working Group, including people with lived experience of autism, has consulted widely with key stakeholders in the design and formulation stage of the project; which has been particularly important in the context of the implementation of a tiered approach to assessment.

Its main work focus is:

- To develop an operational model for a tiered approach to Autism Assessment through developing clear and functioning pathways to services.
- To strengthen Disability, Primary Care and Mental Health services by operating a shared Model of Service.
- An implementation plan to include training which takes cognisance of existing policies of the HSE.

The 2nd and final Phase of the Protocol piloting is now complete, as is the independent evaluation undertaken by the Centre for Effective Services. Following incorporation of learnings from the evaluation and further consultation with professional bodies and civil society, we anticipate that national rollout of the final version of the protocol will commence with training in each of the 6 Health Regions in Quarter 3 2025. The Protocol will be reviewed annually with new learnings incorporated as needs be.

Phase one of the website redevelopment is complete and can be viewed on the HSE website for Autism.

AslAm

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 neurodiversity.

AsIAm (Autism Spectrum Information, Advice and Meeting Point CLG) was, established 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.

The organisation's vision is for Ireland to be a country where all autistic and neurodiverse people are accepted as they are, equal, valued, respected and included.

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.

World Autism Awareness Day

The United Nations General Assembly has marked 2 April on an annual basis, as World Autism Awareness Day (WAAD).

The aim of WAAD is to:

- raise awareness of autism
- actively promote acceptance, appreciation and inclusion
- recognise the contributions autistic people make to their communities and the world at large

Yours Sincerely,

Bernard O Regan Assistant National Director, Access and Integration, Adult Disability Services