**Rialtas na hÉireann** Government of Ireland

# Autism Innovation Strategy

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Prepared by the Department of Children, Equality, Disability, Integration and Youth **gov.ie** 



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# **Guide to document**

We have divided this document into the following sections:

Executive summary	In this section, we provide a short summary of the Autism Innovation Strategy.
Terminology	In this section, we describe what we mean by the key terms we use in the Autism Innovation Strategy.
Context: Developing the Autism Innovation Strategy	In this section, we describe how we developed this Strategy, the approach we took and the consultations we held. We also describe how the Strategy is linked to wider action on disability and equality.
What we were told	In this section, we talk about autism and what we were told during the public consultations. We also provide information on the available data around autism, particularly in the areas of education and health, while recognising that there are gaps in the data available.
What has been done so far	In this section, we give examples of a range of actions that have been undertaken across the public sector to support autistic people and other people with disabilities.
	This is not a comprehensive listing of all that has happened or is happening, and we acknowledge that there are gaps in the services and supports available. The Autism Innovation Strategy aims to progressively address these gaps.

What we are committed to doing under the Autism **Innovation Strategy** 

In this section, we set out what we are committed to doing over the 18-month lifespan of the Autism Innovation Strategy. We have organised these actions and our vision of what needs to be achieved under the following four pillars:

- Pillar 1: Autism-affirming society
- Pillar 2: Equality of access to public services
- Pillar 3: Accessible, inclusive communities, and
- Pillar 4: Building capacity.

Each pillar is divided into themes. Each theme contains individual actions which tell you:

- What the outcome will be for the autistic person and those around them
- What will be done to achieve that outcome, and
- Who will be responsible for delivering on the action.

In this section, we outline how we will go about monitoring and reviewing the implementation of the actions in the Autism Innovation Strategy. In this section you will find two appendices.

> Appendix 1 has more detailed data on autism related to the data provided in Section 2 of the Strategy.

> Appendix 2 provides an alphabetical listing of all the Government Departments, statutory agencies, semi-State companies and other bodies involved in delivering on the Autism Innovation Strategy.

**Monitoring and** implementation

**Appendices** 

# **Executive summary**

The *Programme for Government: Our Shared Future* contains a commitment to national action on autism. This is in recognition of the need to address gaps in existing services and supports for autistic people.

In 2021, the Minister of State with special responsibility for Disability, Anne Rabbitte, announced her intention to develop a new national strategy on autism, the Autism Innovation Strategy.

Development of the Autism Innovation Strategy has involved multiple stages and has been coordinated by the Department of Children, Equality, Disability, Integration and Youth. As a whole-of-government strategy, and in line with the mainstream first approach to disability matters, implementation of actions under the Autism Innovation Strategy will be advanced by Government Departments, statutory agencies and other bodies across government.

Consultation with the autistic community, their families and supporters has been a central part of developing the Autism Innovation Strategy from the beginning. Two public consultations were convened in April 2022 and February 2024 to seek the views of the autistic community, their supporters and other stakeholders.

During the first public consultation in April 2022, respondents told us about the main challenges and barriers facing autistic people and their families in Ireland.

During the second public consultation in February 2024, we asked respondents to reflect on the draft Autism Innovation Strategy. Over 370 individuals and organisations took part in the consultation. Respondents indicated which areas they considered most important under the Strategy and which they felt would have the greatest positive impact. Health and social care and education emerged as key priority areas for most respondents, along with the acceptance and understanding campaign, and autism training.

During both consultations, people told us that autism is an invisible disability that affects different people in different ways. Autistic people can have varying support needs. Being autistic means that an autistic person's brain works in a different way to people who are not autistic. Autistic people are a diverse group, but often they face common challenges because autism is not properly understood or accepted.

The importance of language and terminology around autism emerged as a central issue. Respondents also highlighted gaps in terms of the adequacy and comprehensiveness of existing data and research on autism.

In December 2022, the Autism Innovation Strategy Oversight and Advisory Group was appointed following an application process. The group, which is majority neurodivergent, comprises autistic people as well as professionals, parents and organisations.

Feedback from the autistic community and from other stakeholders has directly informed the vision and approach of the Autism Innovation Strategy.

The Autism Innovation Strategy is also 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.

This engagement process included careful consideration of the recommendations put forward by the Joint Oireachtas Committee on Autism in its final report. This report presented a comprehensive suite of recommendations for improving the lives of autistic people in Ireland. Efforts have been made to reflect these recommendations in the Autism Innovation Strategy, where the Committee's recommendations address unique challenges for autistic people.

Autistic people and other people with disabilities are supported by a range of existing frameworks across government. However, the Autism Innovation Strategy recognises that there is still significant work to be done in order to address gaps in terms of the adequacy and appropriateness of services and supports for autistic people in Ireland.

The Autism Innovation Strategy will provide a framework for cross-government action on autism over an 18-month period. It is designed to complement and enhance wider action on disability by focusing on areas where autistic people face unique challenges and barriers. Existing and planned action to better support people with disabilities, including autistic people, includes the new National Disability Strategy, the Action Plan for Disability Services 2024 – 2026 and the Roadmap for Service Improvement 2023 – 2026: Disability Services for Children and Young People.

The vision for the Autism Innovation Strategy is to provide the building blocks for a more inclusive society, where autistic people are understood and have equity of opportunity to participate in cultural, social and economic life and lead meaningful and fulfilled lives as valued members of the community. In this way, the Autism Innovation Strategy is firmly rooted in the principles of the United Nations Convention on the Rights of Persons with Disabilities. The Strategy aims to support autistic people in a more holistic and coordinated manner through a range of actions that will be delivered over the 18-month lifespan of the Strategy. It also aims to provide a foundation for improved mainstream understanding and accommodation of the needs of autistic people across the public sector and across society.

The Autism Innovation Strategy has four pillars and contains over 80 actions. These actions are organised by theme under the four pillars as follows:

## **Pillar 1: Autism-affirming society**

- Acceptance and understanding
- Autism training in the public sector

## Pillar 2: Equality of access to public services

- Accessibility: Information, services and built environment
- Early learning and childcare
- Education: Primary and post-primary
- Education: Further and higher education
- Employment
- Health and social care
- Justice

## Pillar 3: Accessible, inclusive communities

- Arts and culture
- Libraries
- Public playgrounds
- Sport
- Transport
- In the community

### **Pillar 4: Building capacity**

- Self-advocacy
- Parent support
- Assistive technology
- Data
- Research

The Autism Innovation Strategy is underpinned by a robust and stakeholder-led monitoring and implementation structure. The monitoring structure under the Autism Innovation Strategy will align with the monitoring structure established for the National Disability Strategy.

At the centre of the oversight and monitoring architecture for the Strategy is the Autism Innovation Strategy Oversight and Advisory Group. This group will play a key role in monitoring the Strategy's implementation, and in providing constructive advice to guide whole-of-government work on autism based on the lived experience and expertise of group members.

Implementation of actions by Government Departments, statutory agencies and other bodies will be monitored and assessed through regular progress reports. The Autism Innovation Strategy Oversight and Advisory Group will identify priority actions and escalate these for discussion at meetings of the Autism Innovation Strategy Steering Committee. The Steering Committee will be chaired by the Minister of State with special responsibility for Disability and will comprise representatives from relevant Government Departments and statutory agencies as well as from the Oversight and Advisory Group. The Steering Committee will meet every 6 months.

The Department of Children, Equality, Disability, Integration and Youth, in close cooperation with the Oversight and Advisory Group, will prepare a final report following completion of the Strategy. The report will reflect on the progress achieved under the Autism Innovation Strategy and contain recommendations for further advancing and embedding the mainstream recognition of the needs of autistic people in the future.

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# Terminology

Language is very important to the autistic community. These are some of the key terms we use in the Autism Innovation Strategy, with a brief description of what we mean by these terms. It is also important to acknowledge that language preferences can change and evolve.

Autism	We use this term to refer to everyone who is autistic, recognising that autistic people are individuals with disabilities and have varying support needs.
Autism friendly	We use this term to refer to making modifications to social engagement, communication and physical space, in line with the principles of Universal Design, that best suit autistic people's needs, while acknowledging that this can be different for each autistic person.
Autistic people and other people with disabilities	We use this term to refer to actions in the Autism Innovation Strategy that have relevance to autistic people and to other people with disabilities.
Autistic person	We describe someone as an 'autistic person' rather than saying 'a person with autism'. We use 'identity first' language. This preference was clearly stated in the consultation processes to inform this Strategy. It is important, however, to ask an autistic person what their preference is, as linguistic preferences may vary across the autistic community.
Neuro-affirmative	We use this term to describe a strengths- and rights-based approach to supporting autistic people and affirming their identity, while considering how best to accommodate and support them as individuals.

### Neurodivergent

We use this term to acknowledge that autistic people are neurodivergent and part of a broader neurodivergent community. This community includes people with attention deficit hyperactivity disorder (ADHD), dyscalculia, dyslexia and dyspraxia, among others. Neurodivergent people experience and interact with the world in different ways. While the focus of this Strategy is on autism, some actions may have a broader positive and empowering impact on other neurodivergent people.

There are differing opinions around the use of terms neurodivergent, neurodiversity and neurotypical. The use of these terms and how they are applied in the context of service delivery is evolving, and the use of those terms in this document acknowledges that fact.

# Non-speaking or minimally speaking

We use this term to refer to autistic people who may not use spoken words, who may use some spoken words, or who may not use spoken words all of the time. Not using spoken words does not mean that an autistic person does not communicate, cannot communicate, or does not understand language. Some non-speaking people communicate in other ways using augmentative and alternative means, such as devices, writing, and sign systems. Others communicate through other means, such as sounds, facial expressions, gestures and pointing.

### People with disabilities

We use this term throughout this document. Some people prefer the term 'disabled person' and others prefer 'person with a disability'. The term we use, 'people with disabilities', is informed by the language used in the United Nations Convention on the Rights of Persons with Disabilities. This is reflective of the preamble of the Convention. It emphasises that disability is an evolving concept and that disability results from the interaction between a person and the barriers that hinder their full and effective participation in society on an equal basis with others.

# **1. Context: Developing the Autism Innovation Strategy**

The *Programme for Government: Our Shared Future* contains a commitment to take action on autism. In April 2021, on World Autism Awareness Day, the Minister of State with special responsibility for Disability, Anne Rabbitte, announced her intention to develop the Autism Innovation Strategy as a mechanism for addressing the bespoke challenges facing autistic people and their families in Ireland.

The Department of Children, Equality, Disability, Integration and Youth has coordinated the development of the Autism Innovation Strategy.

The process of developing the Autism Innovation Strategy has involved multiple stages. Consultation with the autistic community, their families and supporters, and other stakeholders has been a central part of developing the Autism Innovation Strategy from the beginning.

An initial public consultation was held between April and May 2022 to gather feedback, opinions and insights into the current challenges facing autistic people and their families. A consultation report summarising and analysing the feedback received from the initial public consultation can be accessed <u>here</u>.

The Autism Innovation Strategy Oversight and Advisory Group was appointed in December 2022, following an application process. The group, which is majority neurodivergent, comprises autistic people as well as professionals, parents and organisations. The group will play an important role in monitoring the Strategy's implementation and providing advice and guidance to inform whole-of-government action on autism.

After the publication of the initial public consultation report and the appointment of the Autism Innovation Strategy Oversight and Advisory Group, work began on preparing a draft of the Autism Innovation Strategy.

As the Strategy is cross-government in nature, extensive bilateral engagements were held with relevant Government Departments and statutory agencies and other bodies to identify actions to respond to the issues raised in the public consultation.<sup>1</sup>

<sup>1</sup> A list of all Government Departments, statutory agencies, semi-State companies and other bodies involved in delivering on the Autism Innovation Strategy is included in Appendix 2.

During this process, consideration was also given to the recommendations in the *Final Report of the Joint Committee on Autism*. Where the Committee's recommendations address unique challenges for autistic people, efforts have been made to reflect these recommendations in the Autism Innovation Strategy.

The draft Autism Innovation Strategy, as well as an easy-to-read version of the draft Strategy, were published in February 2024. A second consultation process began in February 2024 in order to give the autistic community, their supporters and other stakeholders a further opportunity to have their say on the Strategy before it was finalised and launched.

A total of **372** individuals and organisations took part in this **second consultation**.

**353** individuals and organisations provided a **survey response** or written submission.

A further **19 people** took part in targeted consultations with seldom-heard cohorts, including **13 autistic children** and young people and **6** non-speaking and minimally speaking **autistic adults**.

A meeting of the Autism Innovation Strategy Oversight and Advisory Group was also held to discuss the draft Strategy. During this final phase of the public consultation, we asked people for their opinions on different aspects of the draft Strategy, including:

- The clarity and accessibility of the language used in the draft Strategy
- The one thing they most liked about the draft Strategy
- Areas they felt could be improved in the draft Strategy
- Identifying what they considered to be the most important areas for action
- Identifying target audiences and key messages for an acceptance and understanding campaign on autism, and
- Any other comments on the draft Strategy.

The feedback from the second public consultation was carefully collated and analysed. Consultation reports will be published on the Department of Children, Equality, Disability, Integration and Youth website.

The Autism Innovation Strategy reflects the feedback received from the different consultations. It also reflects the 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.

The approach taken in developing the Autism Innovation Strategy was underpinned by several key principles, many of which were identified as important during the public consultations. The key principles are:

- Engagement and consultation with the autistic community, including autistic people, representative organisations, parents, carers and families, and autistic advocates
- An overarching commitment to advancing the human rights and inclusion of autistic people
- Consideration of the challenges experienced by autistic people and their families across the lifespan, and the need to be responsive to different experiences, including those of individuals who need a variety of intensive supports

- The need for tangible actions reflecting key priorities across the lifespan, such as early learning and childcare; education and training; employment; community participation and inclusion; public attitudes; health and well-being outcomes; and data and research
- The need for clear actions with accountabilities for delivery
- Effective, independent oversight to review and monitor progress on actions within the time frame of the Strategy
- Adequate funding for implementation
- High-quality information and training for those working with and supporting autistic people, and
- Coherent linkages to the broader human rights, disability and equality policy context.

In relation to coherence with the broader policy context, it is important that the Autism Innovation Strategy is aligned with the United Nations Convention on the Rights of Persons with Disabilities. Ireland ratified the Convention in 2018. This marked an important milestone in a process to strengthen the rights of people with disabilities in Ireland since Ireland became a signatory to the Convention in 2007. Ireland's approach to meeting the obligations of the Convention is one of progressive realisation.

In addition, the Public Sector Equality and Human Rights Duty is an important mechanism for addressing human rights and equality. The Public Sector Equality and Human Rights Duty is a statutory obligation for public bodies in Section 42 of the Irish Human Rights and Equality Commission Act 2014. Section 42(1) of the Act requires public bodies, in the performance of their functions, to have regard to the need to eliminate discrimination, promote equality and protect the human rights of staff and the people availing of their services.

# 2. What we were told

# Overview

During the different consultation processes that informed the development of the Autism Innovation Strategy, we listened to the views of the autistic community and other stakeholders about their priorities, the challenges they face, and the areas they would like to see included in this Strategy. This section summarises some of the feedback we received.

People told us that autism is an invisible disability that affects different people in different ways. Autistic people can have varying support needs. Being autistic means that an autistic person's brain works in a different way to people who are not autistic. Autism affects the way a person thinks, feels and experiences the world. Autistic traits are not universal and are often specific to each person.

Despite these differences, autistic people share a strong sense of identity. There are some common traits that autistic people often share. These can include sensory processing differences, different communication styles, and a special passion when engaging in their interests.

Autistic people are a diverse group, just as people who are not autistic are, comprising people of all genders, races, backgrounds and ages. Autistic people may also have other health needs.

Autistic people often face a range of challenges because autism is not always properly understood or accepted by people who are not autistic. This lack of understanding can impact on a person's access to services, mental health, access to education and employment, and participation in the community. It can also result in autistic people trying to change or 'mask' in order to belong or fit in, which can be harmful and exhausting.

These challenges may be exacerbated for certain cohorts, such as autistic adults; autistic people who are non-speaking or minimally speaking; autistic women and girls; autistic members of the lesbian, gay, bisexual, transgender, and intersex + community (LGBTI+ community); and autistic members of the Traveller and Roma communities.

### Feedback from public consultations

During the first public consultation, respondents told us about the main challenges and barriers facing autistic people and their families in Ireland. These were expressed in terms of a lack of:

- Alternative forms of communication and robust forms of communication for all non-speaking or minimally speaking autistic people
- Data, as not knowing the actual number of autistic people at any given life stage affects the planning of services required and creates barriers for autistic people in accessing the services they need
- Appropriate education
- Employment opportunities and the impact this has on income adequacy
- Health services and supports
- Neuro-affirmative approaches among some professionals, and
- Understanding among members of the public in their attitudes towards autistic people, which can perpetuate negative stigma, characterising the autistic identity as being one of 'deficit' rather than difference.

During the second public consultation, we asked respondents to reflect on the draft Autism Innovation Strategy. Respondents said they liked the Strategy's potential for impactful change, and its emphasis on rights-focused inclusivity and engagement with autistic people.

Respondents also indicated which areas of the Strategy they considered most important and which areas they felt would have the greatest positive impact. Health and social care and education emerged as key priority areas for most respondents, along with the acceptance and understanding campaign and autism training.

Health and social care, education, and autism training were also the three areas that most respondents felt needed to be improved in the final Strategy.

Respondents provided constructive suggestions about how actions under the Strategy could be strengthened or implemented effectively. They also made suggestions for additional elements and actions to be considered, with an emphasis on identifying measurable actions that will produce tangible results. Another key learning from the consultation process was the importance of engaging with seldom-heard groups. Individuals who participated in the targeted consultations highly valued the opportunity to participate in the consultation process. Non-speaking and minimally speaking participants in particular noted that this was the first time they had been consulted on their views in this way.

### What we know from available data and research

Internationally, there are gaps in the data available on autism. These gaps arise for a number of reasons, including because many autistic people have not been formally identified as autistic, particularly autistic adults and autistic women and girls.

There is evidence that rates of autism identification differ significantly across genders: for example, males are four times more likely than females to be identified as autistic.<sup>2</sup>

Based on the available data at international level, there is evidence of an increase in the number of children being identified as autistic. In the United States of America, identification of autistic children aged 8 years has increased from 1 in 150 children in 2000 to 1 in 36 children in 2020.<sup>3</sup>

In the United Kingdom, the annual school census in England, Northern Ireland, Scotland and Wales has shown a rise in the number of autistic pupils identified by schools. In Northern Ireland, autistic pupils represented 3.2% of pupils by 2018–19.<sup>4</sup>

At national level, there are similar gaps in the adequacy and comprehensiveness of the available data on autism. There is currently no single source of data on autism in Ireland.

<sup>2</sup> Department of Health (2018) *Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population:* A review of data sources and epidemiological studies. Available at: <u>https://www.gov.ie/en/publication/0cc791-</u> reports-on-the-prevalence-of-autism-in-ireland-and-a-review-of-the-s/

<sup>3</sup> Centers for Disease Control and Prevention (2023) *Prevalence and Characteristics of Autism Spectrum Disorder* Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. Available at: <u>https://www.cdc.gov/mmwr/volumes/70/ss/ss7011a1.htm</u>

<sup>4</sup> McConkey, R. (2020) 'The rise in the numbers of pupils identified by schools with autism spectrum disorder (ASD): a comparison of the four countries in the United Kingdom', *Support for Learning*, 35(2), pp. 132–143.

Based on the range of available data, it was estimated in 2018 that autistic people represented between 1.0% and 1.5% of the Irish population.<sup>5</sup> However, drawing on international comparators and the perceived increase in the number of autistic people across a number of national sources, the number of autistic people in Ireland may be higher. Further information on the available national data on autism can be found in Appendix 1 of this document.

In education settings, for example, there has been a steady increase in the number of autistic children availing of special classes and special school places. Based on preliminary data for the 2023-2024 school year, there are more than 14,500 students in autism classes in mainstream primary and post-primary schools. This represents approximately 1.5% of the overall primary and post-primary pupil population.<sup>6</sup> Most of the new provision of additional special classes and special school places in recent years is aimed at supporting autistic children with complex needs. More than 92% of all new special classes and the majority of classes in new special schools are for autistic children.

In health and social care settings, there has been an increase in the number of children being identified as autistic as part of the Statutory Assessment of Need process under the Disability Act 2005. On average, identification of autism constituted 46% of all assessments completed by the Health Service Executive between 2015 and 2023.

Data from the Health Service Executive also show that the number of autistic applicants has increased significantly among school-leavers being profiled for disability day services. Autistic applicants constituted 53% of all school-leaver applicants in 2023.

Data from the National Ability Supports System, which is a national database on disability services, found that in 2022, autism was the most commonly recorded disability type for children (39%) and the fourth most frequently reported primary disability type for adults (5%).<sup>7</sup>

<sup>5</sup> Department of Health (2018) *Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population:* A review of data sources and epidemiological studies. Available at: <u>https://www.gov.ie/en/publication/0cc791-reports-on-the-prevalence-of-autism-in-ireland-and-a-review-of-the-s/</u>

<sup>6</sup> Preliminary figures from the National Council for Special Education and the Department of Education, April 2024.

<sup>7</sup> It is important to note that the data returned for children by the newly established Children's Disability Network Teams are less complete than the data provided by service providers for adults accessing Health Service Executive-funded disability services.

There is a need for improved data on autism in Ireland in order to properly plan for the services and supports that autistic people require.

Research to date on autism has shown that many autistic people have another disability or other health needs, most commonly attention deficit hyperactivity disorder (ADHD), learning disabilities, mood disorders, epilepsy, anxiety, tics and Tourette syndrome.

Research also suggests that autistic people are more likely to have chronic mental and physical health conditions.<sup>8</sup> In the Health Service Executive's *National Clinical Programme for Self-Harm and Suicide-related Ideation*, the autistic community is identified as a group with specific needs in respect of self-harm and suicidal ideation.<sup>9</sup>

A particular challenge for autistic people is the invisibility of autism compared with other disabilities. Some autistic people experience trauma, burnout, anxiety, depression, mental health difficulties, post-traumatic stress disorder and eating disorders because they do not feel properly understood or supported.

There is a need to conduct more research to better understand the profile and lived experiences of autistic people across different ages, genders, sexualities and backgrounds, and with different types of support needs.

<sup>8</sup> Weir, E., Allison, C. and Baron-Cohen, S. (2022) 'Autistic adults have poorer quality healthcare and worse health based on self-report data', *Molecular Autism*, 13(23). Available at: <u>https://doi.org/10.1186/s13229-022-00501-w</u>

<sup>9</sup> Health Service Executive (2022) National Clinical Programme for Self-Harm and Suicide-related Ideation. Available at: <u>https://www.hse.ie/eng/about/who/cspd/ncps/self-harm-suicide-related-ideation/moc/mhncp-self-harm-model-of-care.pdf</u>

# 3. What has been done so far

In recent decades, there has been a significant shift in the disability policy and legislative landscape in Ireland towards a more rights-based and social model of supporting people with disabilities, including autistic people.

Ireland's ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2018 has added further momentum to this process. In line with the Convention, a key focus is ensuring that people with disabilities are supported to live full lives of their choosing in the community, as well as achieving better outcomes for persons with disabilities.

It is important that the Autism Innovation Strategy is informed by, and informs, wider action on disability. The Autism Innovation Strategy will target the unique challenges facing autistic people and their families. The Strategy will complement a number of broader disability initiatives which aim to address shared challenges for people with disabilities in Ireland.

For example, efforts are under way to develop a new National Disability Strategy. The new strategy will provide a blueprint, developed in partnership with people with disabilities, for an ambitious programme of work to coordinate continued implementation of the Convention and to further support the rights and inclusion of all people with disabilities.

In addition, in recognition of the need to provide tangible improvements for all people supported by disability services, the Action Plan for Disability Services 2024 – 2026 sets out a 3-year programme for improving capacity in and access to disability services. It also aims to ensure that services are person-centred and give individuals choice and control, in line with the Convention.

In relation to improving the quality of and access to services for children with a disability who have complex needs, the Roadmap for Service Improvement 2023 – 2026: Disability Services for Children and Young People sets out a suite of actions that are designed to enhance the provision of children's disability services in Ireland and better support children and their families. The Roadmap seeks to deliver improvements in key areas such as integrated service delivery, access to services and assessment, workforce planning, engagement with families, and improved pathways between health and social care services and education services.

In addition to these broader reform initiatives, autistic people and other people with disabilities are supported by a range of existing bespoke and mainstream initiatives across government. Some of these areas are highlighted below.

### Arts, culture and sport

- National museums and galleries provide a range of bespoke supports for autistic people. For example, the National Museum of Ireland has a social story and sensory maps for the National Museum of Ireland – Country Life museum in Castlebar. On request, the National Gallery of Ireland can arrange quiet spaces around the Gallery. The Gallery also provides ear defenders and ear plugs and runs extensive programs for the neurodivergent community, including autistic individuals and groups.
- The National Museum of Ireland has secured AsIAM as a collaborative partner to work with the Museum towards AsIAM Autism-Friendly accreditation. This will involve training for teams across its sites, the development of a Charter of Inclusion and an overall Sensory Environmental Assessment.
- Sport Ireland supports a range of initiatives and programmes through its Sports Inclusion Disability Programme. Such initiatives include dedicated programmes developed for autistic people, such as the Autism in Sport workshop.

### **Early learning and childcare**

- The Access and Inclusion Model aims to create a more inclusive environment in pre-schools by providing universal supports to pre-school settings, as well as targeted supports that focus on the needs of the individual child.
- Guidelines on Universal Design have been developed for early learning and care settings so that they include all children, including those with disabilities.
- A sensory processing e-learning training has been developed for educators.

## **Education**

- Additional supports have been provided in mainstream schools, including extra special education teachers and special needs assistants.
- Enhanced arrangements have been put in place for planning, funding and coordinating the provision of special classes and special school places, including the opening of new special schools and additional special class provision.
- Funding has been provided for assistive technology supports.
- Steps have been taken to promote Universal Design principles both for school buildings and for learning in order to create an inclusive learning environment for all.
- The Middletown Centre for Autism (which is jointly funded by the Department of Education in the Republic of Ireland and the Department of Education in Northern Ireland) offers professional and parental training programmes and assessment and intervention supports.

### Employment

- Intreo centres (which provide employment and income supports and services) have begun identifying quiet, calm rooms to support autistic users.
- The Public Appointments Service provides a range of reasonable accommodations for candidates with a disability as part of the recruitment and selection process.
- Inclusive workspaces have been developed within the Connected Hubs network.

### **Further and higher education**

- The Fund for Students with Disabilities provides funding to further and higher education institutions in order to assist them in offering supports and services to students with a disability and to autistic students so that they can access, fully participate in and successfully complete their chosen course of study.
- Funding has been provided under the Programme for Access to Higher Education (PATH 4) to support inclusive, universally designed higher education environments for all students, including autistic students and students with an intellectual disability.

### Health and social care

- Under the Health Service Executive Service Improvement Programme for the Autistic Community, work is under way to develop a standardised assessment approach for use in all services dealing with the assessment of autistic people.
- A programme of accessible information is also being developed for autistic people and their families, as well as carers and service providers.
- The Health Service Executive has provided €1 million in funding for the Augmentative and Alternative Communication Support Programme, which will provide information and training to support users and those around them. Funding will also be used to purchase devices.
- Funding has been provided for the organisation AsIAm to operate an Autism Information Line. This information line provides telephone, email and instant messaging support for autistic people and their families.

### Housing

- Autistic people are represented as part of the monitoring structure for the implementation of the National Housing Strategy for Disabled People 2022-2027.
- The Housing Adaptation Grant for People with a Disability is available to assist in the completion of works that are reasonably necessary in order to make a house more suitable for a person with an enduring disability, including sensory disabilities.

 Regional interagency groups have been established under the National Housing Strategy for Disabled People 2022-2027 for the sharing of best practice on supporting people with disabilities in applying for social housing support across the local authorities.

# In the community

• Sensory services have been provided in public libraries, including sensory pods, sensory toys and other resources.

# Justice

- The Just a Minute (JAM) Card has been rolled out across the Courts Service. Over 75% of Courts Service staff have received JAM training, and it is part of induction training for all new staff.
- Within An Garda Síochána there are a number of existing training initiatives around autism, including for trainee gardaí.
- The Irish Prison Service and the Probation Service have established a number of training and development initiatives aimed at increasing knowledge in relation to supporting autistic people.

# Transport

- Customer-facing staff in public transport companies are required to receive disability awareness training. This includes training on all types of disabilities, including autism, which must be renewed every 3 years.
- The Prepare me AsIAm<sup>10</sup> for Public Transport initiative has been launched to support autistic people in planning and using public transport through videos, photographs and storyboards.
- The JAM Card has been rolled out, which allows autistic people and others to discreetly tell others that they need 'just a minute' of patience when using public transport.
- In 2023, Irish Rail distributed 1,500 sensory packs to autistic passengers. These packs include ear defenders, a fidget spinner, sunglasses and a storyboard.

The Autism Innovation Strategy recognises that there is still significant work to do to support autistic people in Ireland. The Strategy will further advance existing work through a suite of actions designed to provide tangible solutions to the challenges, needs and experiences of autistic people and to build a solid foundation for improved services and supports in the future.

<sup>10</sup> Transport for Ireland (n.d.) *Prepare me...As I am*. Available at: <u>https://www.transportforireland.ie/prepare-me-as-i-am/</u>

# 4. What we are committed to doing under the Autism Innovation Strategy

# Vision, principles and values

The Autism Innovation Strategy will provide a framework for cross-government action on autism. It is designed to complement and enhance wider action on disability and address gaps in existing services and supports. The Strategy identifies simple additional actions that can be delivered within an 18-month time frame and that can provide a foundation for improved services and supports for autistic people.

The vision for the Autism Innovation Strategy is to provide the building blocks for a more inclusive society, where autistic people are understood and have equity of opportunity to participate in cultural, social and economic life and lead meaningful and fulfilled lives as valued members of the community.

The Strategy aims to support autistic people in a more holistic and coordinated manner through a range of actions that will be delivered over the 18-month lifespan of the Strategy. It also aims to provide a foundation for improved mainstream understanding and accommodation of the needs of autistic people across the public sector and across society in the future.

The United Nations Convention on the Rights of Persons with Disabilities establishes a framework for the promotion and protection of the rights of people with disabilities. Its fundamental principles are laid down in Article 3. In summary, these principles are as follows:

- People with disabilities are free to make their own choices.
- No one will be discriminated against.
- People with disabilities have the same rights to be included in society as anybody else.
- People with disabilities are to be respected for who they are.
- Everyone should have equal access.
- Everyone should have equal opportunities, regardless of gender identity and expression.
- Children with disabilities should be respected for who they are as they grow up.

These guiding principles inform the values that underpin the Autism Innovation Strategy, which are:

- Rights focused
- Person-centred
- Neuro-affirmative, and
- Delivered within the mainstream, where possible.

The primary target group of actions under the Autism Innovation Strategy is autistic people and, in some cases, their families. Some actions in the Strategy focus on autistic children, some focus on autistic adults and some are designed to support autistic people across the lifespan.

While the focus of the Strategy is on autism, some of the actions could also have a broader positive and empowering impact on all neurodivergent people and other people with disabilities.

# What we will do

The Autism Innovation Strategy has four pillars:

- 1. Autism-affirming society
- 2. Equality of access to public services<sup>11</sup>
- 3. Accessible, inclusive communities, and
- 4. Building capacity.

Each pillar of the Strategy includes a vision statement and a number of actions that will be delivered by a range of Government Departments, statutory agencies and bodies, with the aim of achieving them within the 18-month time frame of this Strategy. The actions under each of the pillars are organised by theme.

The text of each action begins with the outcome that the action will seek to achieve within this time frame. Delivery of the actions will be monitored and overseen in line with the process set out in Section 5.

<sup>11</sup> Public services include services delivered by Government Departments, State agencies and organisations in receipt of State funding.

# **Pillar 1: Autism-affirming society**

Our vision is to significantly enhance public understanding of autism and autistic people and to affirm autistic people as individuals who have a valued role in society.

We aim to achieve this through the actions outlined below.

# Acceptance and understanding

To inform the development of a national autism acceptance and understanding campaign, we will synthesise existing data on attitudes towards autistic people in Ireland. We will consult with autistic people to ensure that this exercise is reflective of their lived experience.

Lead: National Disability Authority

**Supported by:** Department of Children, Equality, Disability, Integration and Youth



1

To promote greater acceptance and understanding of autism in Ireland, we will initiate a national autism acceptance and understanding campaign. This will be co-designed with the autistic community.

# Lead:

Department of Children, Equality, Disability, Integration and Youth; National Disability Authority 3

To ensure that the autistic experience is appropriately represented in the media, we will seek to promote initiatives to support diversity in the media. This will include the appropriate representation of the autistic experience and the accurate and inclusive portrayal of autistic people as part of our Gender, Equality, Diversity and Inclusion Strategy.

**Lead:** Coimisiún na Meán

### Supported by:

Department of Tourism, Culture, Arts, Gaeltacht, Sport and Media

We will establish an Autism Innovation Fund. The aim of this fund will be twofold:

- To provide funding for innovative projects, initiatives and activities designed to support and empower autistic people around Ireland.
- To support research which aims to increase our understanding of autism and autistic people, in particular where research aims to fill a gap in data or knowledge, or concerns the rights of autistic people. This could include in intersectional contexts, such as the experiences of autistic people with other identities, including gender, migrant, LGBTQI+, Traveller and Roma identities, and so forth, or on better understanding issues like the experiences of autistic people who experience Domestic or Gender Based Violence.

#### Lead:

Department of Children, Equality, Disability, Integration and Youth

## Autism training in the public sector

5

To promote improved understanding of autism across the public sector, we 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.

### Lead:

National Disability Authority

#### Supported by:

Department of Children, Equality, Disability, Integration and Youth



To develop a coherent, neuro-affirmative approach to autism training in the public sector, we will coordinate the development of a good practice guidance document. This document will inform the provision of future autism training initiatives across the public sector, and will be developed in consultation with the autistic community.

Lead: National Disability Authority

### Supported by:

Department of Children, Equality, Disability, Integration and Youth; Health Service Executive; Department of Education

# 7

To promote neuro-affirmative models of practice by staff in the health and social care sector, we will support 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. We will explore making this training mandatory for certain priority staff groups and rolling out the training more widely across the public sector. The training will be co-designed, co-developed and co-delivered with autistic people and will include:

- The development of specific autism modules
- The development of modules for relevant co-occurring conditions, and
- The development and launch of a Knowledge Hub on HSeLanD for professionals.

Lead: Health Service Executive

### Supported by:

Department of Children, Equality, Disability, Integration and Youth

8

To enhance the skills and competencies of staff in understanding autism, we will source and facilitate bespoke training on autism, including communication methods, for frontline staff delivering the National Clinical Programme for Self-Harm and Suicide-related Ideation. This training will be designed and delivered with/by autistic people.

Lead: Health Service Executive

# 9

To better support autistic people in accessing health and social care services, we will provide training to Health Service Executive Access Officers on the Health Service Executive's revised National Guidelines on Accessible Health and Social Care Services. This training will place a particular emphasis on enhancing the skills and competencies of Access Officers in understanding autism and the supports that autistic people may require when accessing health and social care services.

Lead: Health Service Executive

Supported by: National Disability Authority



To promote good practice in supporting autistic pupils in schools, we will raise awareness and provide training in order to advance the rollout of the Autism Good Practice Guidance for Schools. We will ensure that this Guidance is reviewed on an ongoing basis to reflect evolving preferences and developments in approaches and practices to support autistic students.

Lead: Department of Education

### Supported by:

National Council for Special Education

11

To better support autistic people using Citizens Information Services and the National Advocacy Service for People with Disabilities, we will support staff in Citizens Information Board-funded companies to access and engage with the new public sector e-learning training module being developed on disability equality, which includes consideration of the unique needs of autistic people. This foundational learning tool will provide a basis for identifying further actions and supports that may be required.

Lead:

**Citizens Information Board** 

### Supported by:

Citizen Information Board-funded companies, including Citizens Information Services and the National Advocacy Service for People with Disabilities; Department of Social Protection

# Pillar 2: Equality of access to public services

Our vision is to provide autistic people with high-quality and accessible public services across the lifespan which respect the identity and autonomy of autistic people.

We aim to achieve this through the actions outlined below.

# Accessibility: Information, services and built environment

To demonstrate that the needs of autistic people are an integral part of the design of the built environment, products, services, and information communication technologies, we will:

- Develop and publish practical examples of how autistic people's needs can be incorporated within the concept of Universal Design, and
- Ensure that the Code of Practice on Accessible Public Buildings and the Code of Practice on Accessibility of Public Services and Information provided by Public Bodies include consideration of the needs of autistic people.

Lead: National Disability Authority

13

12

To provide a common terminology framework relating to autism across the public sector, we will review the National Disability Authority's *Advice Paper on Disability Language and Terminology*. We will do this in consultation with autistic people to ensure that it reflects the preferences of the autistic community.

Lead: National Disability Authority 14

To improve the accessibility of health and social care services, we will ensure that the review of the Health Service Executive's National Guidelines on Accessible Health and Social Care Services includes consideration of the needs of autistic people accessing these services.

Lead: Health Service Executive

# 15

To ensure the accessibility and user friendliness of MyWelfare scheme applications, we will consult with autistic customers and other people with a disability as part of the process to digitalise applications for disability schemes on MyWelfare.

Lead: Department of Social Protection



To improve the accessibility of Road Safety Authority services for autistic users, we will identify what autism-specific supports could be provided in the delivery of Road Safety Authority services, particularly around the driver theory test and driving licensing services.

Lead: Road Safety Authority

Supported by: Department of Transport



To ensure that autistic people have access to up-to-date information on relevant services and supports, we will signpost and provide links to relevant information for autistic people. This will be provided on <u>citizensinformation.ie</u> and in the *Guide to entitlements for people with disabilities*. It will cover information on services and supports (including assistive technology) hosted on other public sector sites.

Lead: Citizens Information Board

Supported by: Department of Social Protection To ensure that autistic people have quick and efficient access to relevant information on services, we will continue to support the pilot National Autism Information Line and conduct a timely assessment of its impact so we can capture learnings and enhance support for families.

Lead: Health Service Executive

# Early learning and childcare

To support the inclusion of autistic children in mainstream early learning and childcare, we will ensure that professional support and advisory services include neuro-affirmative guidance around the needs of autistic children. This will be informed by the findings of the Access and Inclusion Model review.

#### Lead:

Department of Children, Equality, Disability, Integration and Youth

To support inclusive and accessible learning environments, we will provide continuing professional development, support and written guidance material to early years educators and school-age childcare practitioners. This will include guidance on the provision of optimal early learning and childcare environments which recognise the varying sensory needs of autistic children. This will be informed by the findings of the Access and Inclusion Model review.

#### Lead:

Department of Children, Equality, Disability, Integration and Youth

20

21

To ensure that autistic children are supported in moving between different settings, we will ensure that the needs of autistic children are considered as part of efforts to develop a national policy on transitions for all children from home into and through early learning and childcare and on to primary school. The transition policy will be supported by a national model of transitions in practice informed by the findings of the Access and Inclusion Model review.

# Lead:

Department of Children, Equality, Disability, Integration and Youth; Department of Education

# Supported by:

National Council for Special Education



To ensure that the programmes and practices in early intervention programmes are leading to improved outcomes for autistic children, we will commence a process of quality assuring provision in early intervention classes for autistic children. The inspection process will consider how children's needs are being identified and met. It will also consider how outcomes are monitored and how inclusive practices are implemented.

## Lead:

Department of Education Inspectorate

Supported by: Department of Education

# **Education: Primary and post-primary**



To provide additional professional development supports for schools in supporting autistic students, we will expand the Autism Team in the National Council for Special Education. This team will provide a range of services, including educational autism supports and evidence-informed best practice models for learners across sectors.

# Lead:

Department of Education

# Supporting: National Council for Special Education

24

To provide opportunities for autistic students and others with special educational needs to engage with peers in both mainstream and special schools, we will support schools to implement the Towards Inclusion programme. We will provide funding to the National Council for Special Education to coordinate and evaluate the programme. We will also provide small-scale grants to participant schools in order to assist in offsetting incurred expenses, including the cost of travel between schools.

#### Lead:

Department of Education

Supported by: National Council for Special Education

To ensure that parents and education professionals have access to autism best practice and training, we will continue to work with the Middletown Centre for Autism to guide the development of their service in line with a neuro-affirmative and inclusive education system. We will seek opportunities to extend its services where appropriate. In addition, we will work closely with our partners in the Department of Education in Northern Ireland to explore the provision of additional funding.

Lead: Department of Education

26

25

To support autistic students and other students with special needs to access the Summer Programme, we will ensure that mainstream schools and special schools continue to be supported to offer a Summer Programme in 2024 and 2025.

Lead: Department of Education

### **Education: Further and higher education**

To support an inclusive experience for autistic students in further and higher education, we will continue to roll out the Universal Design for Learning Badge across further education and training institutions. We will also consider the provision of additional funding to higher education institutions for Universal Design initiatives in order to support them in making their campuses more autism friendly.

#### Lead:

Department of Further and Higher Education, Research, Innovation and Science

#### Supported by:

Higher Education Authority; SOLAS; further and higher education institutions



27

To support the greater inclusion of priority groups, including autistic students, in further and higher education, we will provide funding (to be utilised in 2024) under PATH 4. This funding will be used to prioritise measures identified in the *Final Report of the Joint Committee on Autism*, including:

- Compiling sensory maps of campuses, and
- Providing more autism-friendly tours of campuses throughout the year.

#### Lead:

Department of Further and Higher Education, Research, Innovation and Science

# 29

To support autistic people to participate in apprenticeships, we will engage with the Access and Inclusion subcommittee of the National Apprenticeship Alliance in order to clearly identify the type and level of supports required to ensure that autistic people can participate in apprenticeships in line with the *Action Plan for Apprenticeship 2021– 2025*. The Access and Inclusion subcommittee will consider the support needs of under-represented people, including autistic people, as part of its work for 2024.

#### Lead:

Department of Children, Equality, Disability, Integration and Youth

#### Supported by:

Department of Further and Higher Education, Research, Innovation and Science

# 30

To support autistic students and other students with a disability in their college journey, we will progressively expand the scope of the Fund for Students with Disabilities within the further education sector.

#### Lead:

Department of Further and Higher Education, Research, Innovation and Science

31

To improve the learning experience and to provide an improved pathway to employment, we will commence specially designed courses for students with an intellectual disability, including autistic students with an intellectual disability, in 10 higher education institutions across the country in September 2024. A number of these enhanced courses will include work experience opportunities.

#### Lead:

Department of Further and Higher Education, Research, Innovation and Science

### **Employment**



To enable employers to better support autistic employees in the workplace, we will review existing resources relating to autism-friendly workplaces. As part of this review, we will identify gaps in information and/or the need to update information. This will include guidance on accommodating people with sensory processing differences in openplan offices.

Lead:

National Disability Authority

#### Supported by:

Department of Enterprise, Trade and Employment



To enhance our knowledge and understanding of autism and diversity in the recruitment market and the Irish civil and public sector, we will continue to gather equality monitoring data in order to improve our service offering, including the provision of appropriate reasonable accommodations. This will support the commitment to increase the number of candidates with a declared disability, including autistic people, applying for roles.

Lead: Public Appointments Service



To promote remote working and entrepreneurial opportunities for autistic people, we will highlight autism-friendly workspaces within Connected Hubs (an online booking and payments platform for remote working facilities located across the country) by 2025.

#### Lead:

Department of Rural and Community Development

#### Supported by:

Western Development Commission

# To better understand the needs of autistic candidates and others, we will collect data on reasonable accommodation requests and requirements from candidates in order to help inform future recruitment policies and processes.

Lead: Public Appointments Service

**Supported by:** Department of Public Expenditure, NDP Delivery and Reform

36

35

To ensure that Intreo (the Public Employment Service) effectively supports employment service staff to address employment opportunities and challenges for people with disabilities, including autistic people, we will review our disability awareness training.

Lead: Department of Social Protection

Supported by: Intreo

37

To ensure a supportive environment for autistic people and others with sensory processing differences in accessing and using Intreo employment services, we will ensure that a quiet, calm room is available in each Intreo office by the end of the first quarter of 2025.

Lead: Department of Social Protection

Supported by: Intreo

38

To ensure that all employees in the civil service, including autistic people, can carry out their work on an equal footing with others, we will ensure that consideration is given to the needs of autistic staff, along with other cohorts, in the context of our review of disability inclusion policies and procedures.

Lead:

Department of Public Expenditure, NDP Delivery and Reform



To support entrepreneurship opportunities for autistic people, Local Enterprise Offices will adapt their entrepreneurship training and mentoring programmes, in consultation with the relevant representative organisation, so as to better support their needs, alongside other underrepresented groups, in line with best practice.

#### Lead:

Department of Enterprise, Trade and Employment

#### Supported by: Local authorities



To ensure equitable opportunities for all candidates, including autistic people, we will continue to enhance our recruitment and selection processes for the full range of job types within our mandate by taking a Universal Design-led approach in collaboration with our clients and candidates.

Lead: Public Appointments Service

#### Supported by:

National Disability Authority; Department of Public Expenditure, NPD Delivery and Reform



To support diversity and inclusion in the broadcasting and creative media sector, including for autistic people, we will support and promote initiatives for autism-inclusive employment and recruitment outreach and support both career access and career development of autistic people within the sector.

Lead: Coimisiún na Meán

# Supported by:

Department of Tourism, Culture, Arts, Gaeltacht, Sport and Media

#### Health and social care

To support engagement with autistic people regarding their needs and preferences for support services, we will co-design with autistic people and other people with a disability, a guidance document that will support people with a disability to engage in effective decision-making about the design and implementation of their Health Service Executivefunded support services.

Lead: Health Service Executive



42

To improve information and support for autistic people and their families, we will develop evidence-based centres of information on autism services in two Community Healthcare Organisations using a one-stop-shop approach. We will do this in conjunction with relevant partners. The purpose of these centres will be to scale up existing services and provide a coordinated, effective, neuro-affirmative, evidence-based destination where autistic adults, children and their families can receive information and direct support.

#### Lead:

Health Service Executive

#### Supported by:

Department of Children, Equality, Disability, Integration and Youth; Department of Health

44

To provide clear and accessible information to support autistic people and their families, we will develop information on the Health Service Executive website and in video and printed brochure forms. This information will cover common co-occuring conditions associated with autism and neurodivergence. It will also include local signposting information. This will encompass how and where autistic people and others can access support services from the full range of health and social care service providers.

Lead: Health Service Executive



To commence work to establish a public pathway to neuro-affirmative assessment and interventions for autistic adults, we will roll out a demonstrator project in one Regional Health Area. This will inform the national roll-out of the pathway. Autistic people will be consulted on, and will co-design, this national roll-out.

#### Lead:

Health Service Executive

#### Supported by:

Department of Children, Equality, Disability, Integration and Youth; Department of Health



To enable autistic children and adolescents to access early intervention, assessment and multidisciplinary therapy supports, we will allocate resources to reform efforts under the *Roadmap for Service Improvement* 2023 – 2026: *Disability Services for Children and Young People*. Within the context of the Roadmap, Government Departments and statutory agencies will collaborate in order to ensure that the implementation of these actions and the Roadmap will also enable greater engagement and communication with families.

Lead: Health Service Executive

## Supported by:

Department of Children, Equality, Disability, Integration and Youth



To better address the needs of people using specialist disability supports, including autistic people, we will provide additional resources for building capacity and making specialist disability services more person-centred under the Action Plan for Disability Services 2024 – 2026.

Lead: Health Service Executive

**Supported by:** Department of Children, Equality, Disability, Integration and Youth Department of Children, Equality, Disability, Integration and Youth

To enable autistic children, adolescents and adults to access appropriate mental health, primary care and specialist disability services, we will continue the development of early intervention and assessment services guided by a shared care approach, by:

- Allocating resources to complete the piloting and evaluation of the current Autism Assessment and Intervention Pathways protocol
- Supporting the production of an independent evaluation report on the service user and service provider experience of using the Autism Assessment and Intervention Pathways protocol, and
- Incorporating key learnings and recommendations arising from Phase 1 and Phase 2 of the piloting into a revised protocol for national rollout across mental health, primary care and disability services.

Lead:

Health Service Executive

#### Supported by:

Department of Children, Equality, Disability, Integration and Youth; Department of Health

49

48

To provide relevant mental health services to autistic adolescents and adults with substance use problems, we will progress the development of clear and integrated care pathways for people with a dual diagnosis. This will include the implementation of the Model of Care for Dual Diagnosis (2023), by:

- Developing a detailed implementation plan and bespoke training programme, and
- Establishing initial sites, including recruitment of teams and base locations, subject to funding allocation.

Lead: Health Service Executive

# Supported by:

Department of Health

50

To ensure continuity of care and support for autistic people with particular vulnerabilities and increased risk of suicide, as part of the development of the successor strategy to Connecting for Life, we will ensure that consultation processes and associated evidence bases include appropriate inclusion and reference to priority groups, including autistic people.

#### Lead:

Department of Health

#### Supported by:

Health Service Executive National Office for Suicide Prevention



To provide appropriate support to vulnerable autistic people within the community, we will develop targeted and appropriate suicide prevention information and training.

Lead: Health Service Executive National Office for Suicide Prevention

Supported by: Department of Health



To support young people who will be transitioning into disability day services to use public transport, we will introduce a pilot in one Regional Health Area for final year students to gain experience travelling on public transport.

Lead: Health Service Executive

**Supported by:** Department of Children, Equality, Disability, Integration and Youth



To address the needs of autistic people using Health Service Executivefunded day services, we will work to develop the resources to support day service providers to meet the needs of autistic people. This will include:

- Providing information on the Health Service Executive website that includes signposting information on how and where autistic people and others can access support services, and
- Rolling out a person-centred planning eLearning module for staff.

Lead: Health Service Executive

#### Supported by:

Department of Children, Equality, Disability, Integration and Youth

54

To support improved access to respite services, in the context of work under way to expand and improve respite services, we will ensure that this process is informed by the needs of autistic people and their families.

#### Lead:

Health Service Executive

#### Supported by:

Department of Children, Equality, Disability, Integration and Youth

#### Justice



To support autistic people navigating the courts system, we will ensure, in line with Government Design Principle 2, that consideration is given to the needs of autistic people and other people with disabilities as part of the design of our customer service journey. As part of this process, we will consult with autistic people and others with a disability. We will consider supports that could be offered to allow people to better understand and prepare in advance for the experience of attending court, as far as is reasonably practicable.

Lead: The Courts Service



To better support autistic people interacting with the Irish Prison Service in a coordinated manner, we will continue to advance efforts to support the development of Autism Accreditation Standards for the Irish Prison Service. These standards will establish national custodial standards for autistic people in custody and autistic family members of people in custody.

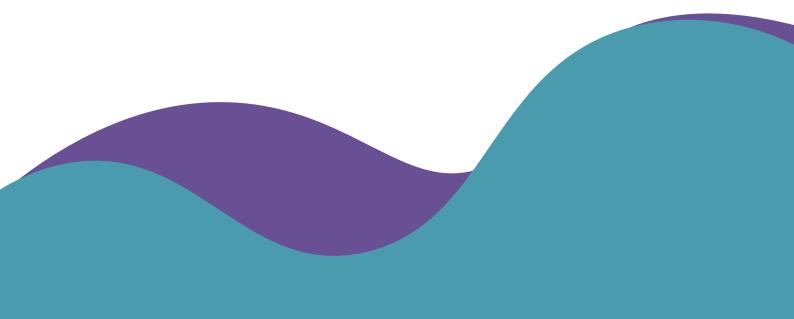
Lead: Irish Prison Service

Supported by: Department of Justice



To improve understanding of autistic people within the justice system, we will revise existing guidance for justice professionals on how to communicate with and support autistic people. We will do this in collaboration with autistic people.

Lead: National Disability Authority



# Pillar 3: Accessible, inclusive communities

Our vision is to create accessible, inclusive communities where autistic people have equal opportunities to belong.

We aim to achieve this through the actions outlined below.

# Arts and culture

58

To promote a positive experience for autistic people visiting national cultural institutions, we will support these facilities to be accessible to autistic people in line with the principles of Universal Design. This will include building on good practice for autistic people, such as identifying and incorporating quiet spaces throughout the building; reviewing accessibility maps of galleries; providing ear plugs/ear defenders; and providing sensory-friendly events for autistic people who may find the sensory environment challenging.

#### Lead:

National cultural institutions (the National Museum of Ireland, the National Gallery of Ireland, the Irish Museum of Modern Art (IMMA), the Chester Beatty, the National Concert Hall (NCH), the Crawford Art Gallery, the National Library of Ireland (NLI), and the National Archives)

#### Supported by:

Department of Tourism, Culture, Arts, Gaeltacht, Sport and Media



To enhance autistic people's experience of our national cultural institutions, we will support staff working in these facilities to avail of autism training. We consider this to be an important component of disability awareness and understanding training. Such training will enhance staff members' skills and competencies in enabling autistic children, young people and adults to engage with and experience our national cultural institutions in a meaningful way. We will inform users of the supports available, for example through targeted outreach.

#### Lead:

National cultural institutions (the National Museum of Ireland, the National Gallery of Ireland, the Irish Museum of Modern Art (IMMA), the Chester Beatty, the National Concert Hall (NCH), the Crawford Art Gallery, the National Library of Ireland (NLI), and the National Archives)

#### Supported by:

Department of Tourism, Culture, Arts, Gaeltacht, Sport and Media

#### Libraries



To support autistic people in accessing the public library service, we will ensure that the needs of autistic service users and other people with a disability are taken into account under *The Library is the Place: Information, Recreation, Inspiration – National Public Library Strategy 2023-2027.* To achieve this, we will ensure that training is made available to library staff. Such training will provide guidance on tailoring library service provision to support autistic service users.

#### Lead:

Department of Rural and Community Development

#### Supported by:

Public library service; Local Government Management Agency

# **Public playgrounds**

To make playgrounds inclusive, enjoyable and accessible for all children, including autistic children, we will expand the installation of communication boards in public playgrounds across all local authorities.

Lead:

County and City Management Association; local authorities

# Sport

61

To support the full participation and inclusion of autistic people in sport, we will ensure that the needs of autistic people are recognised in the review and update of the *Sport Ireland Policy on Participation in Sport by People with Disabilities*, which is due for completion in 2024.

#### Lead:

Sport Ireland

#### Supported by:

Department of Tourism, Culture, Arts, Gaeltacht, Sport and Media; wider sport sector organisations

63

To ensure that staff within the sport sector are appropriately trained to facilitate the participation of autistic people in local sport, we will work with partners to support the roll-out of training in each county. This training will be designed to raise awareness and understanding of inclusive practices for autistic people's participation in sport.

Lead: Sport Ireland

#### Supported by:

Department of Tourism, Culture, Arts, Gaeltacht, Sport and Media; wider sport sector organisations



To provide opportunities for autistic people to engage in sport and physical activity generally and specifically in the outdoors, through the administration of dormant accounts funding, we will support the delivery of programmes and initiatives across the sport and outdoors sector to encourage autistic people's participation in sport. We will provide a platform at our regular networking and information events to share best practice examples across the sport sector.

#### Lead:

Sport Ireland

#### Supported by:

Department of Tourism, Culture, Arts, Gaeltacht, Sport and Media; wider sport sector organisations

# Transport



To ensure a positive travel experience for autistic people and their families when travelling by air, we will introduce additional pre-flight supports in our three State airports (Cork, Dublin and Shannon), such as:

- The development of storyboards specific to each airport
- The development of pre-travel visual guides of each airport, and
- Consideration of the installation of an additional sensory room at Dublin Airport.

We will also ensure that these autism supports are publicised in order to raise awareness of the supports available.

#### Lead:

daa plc (the operator and manager of Dublin and Cork airports); The Shannon Airport Group

Supported by: Department of Transport

# To support autistic passengers on cross-border rail services, we will engage with Translink to offer quieter train carriages on the Dublin to Belfast lines.

Lead: Irish Rail

Supported by: Department of Transport; Translink



66

To support autistic passengers to travel independently and with confidence using public transport, we will expand the Travel Assistance Scheme currently being provided in Dublin and Cork to Limerick, Galway in 2024 and Waterford in 2025. This scheme supports people with disabilities, including autistic people, to travel with confidence.

Lead: National Transport Authority

Supported by: Department of Transport

#### In the community

To build on existing efforts at local government level to support autistic people in the community, we will engage in the sharing of information and best practice on supporting autistic people across the local government sector through existing programmes and forums.

Lead:

County and City Management Association; local authorities



68

To support autistic people to engage in events in the community, the local government sector will further develop the work undertaken within the sector to assist in making funded events and festivals accessible for all, including for autistic people.

#### Lead:

County and City Management Association; local authorities

# 70

To make communities more inclusive and to empower individuals to improve their quality of life and access employment, we will deliver supports to autistic people and other people with disabilities through the Social Inclusion and Community Activation Programme (SICAP).

#### Lead:

Department of Rural and Community Development



To address the sensory needs of autistic children and adults, we will continue to provide funding for a range of sensory initiatives, community groups and organisations to create a more inclusive environment for autistic people and other people with sensory processing differences.

Lead: Health Services Executive

**Supported by:** Department of Children, Equality, Disability, Integration and Youth

# **Pillar 4: Building capacity**

# Our vision is to empower autistic people to be able to live the life they choose.

We aim to achieve this through the actions outlined below.

# Self-advocacy

72

To build the capacity of Disabled Persons Organisations representing autistic people to engage in advocacy, we will ensure that capacitybuilding initiatives under the National Disability Strategy are inclusive of autistic people.

Lead:

Department of Children, Equality, Disability, Integration and Youth

#### **Parent support**

To support autistic people and their families following a formal identification of autism, we will develop a new Health Service Executive autism information website. This will offer a means of providing support and information to autistic people and their families.

Lead: Health Service Executive

74

73

To assist the parents of non-speaking or minimally speaking autistic children, we will provide training for public health nurses through the roll-out of the autism training framework in order to inform and assist parents in supporting their children.

Lead: Health Service Executive



To provide parents of autistic children with information on digital and assistive technology, we will develop an introductory guide on finding the right assistive technology. The guide will contain information on communication aids, as well as on what Augmentative and Alternative Communication is and how to access it. It will be co-designed with users of assistive technology, including autistic people.

#### Lead:

Health Service Executive

#### Supported by:

Department of Children, Equality, Disability, Integration and Youth

# Assistive technology



To enhance the knowledge and competencies of education, health and social care professionals with regard to autism and assistive technology, we will provide training on the range of assistive products, technology, and forms of Augmentative and Alternative Communication that can help autistic people express themselves and better engage in daily activities.

Lead: Health Service Executive

#### Supported by:

Department of Education; relevant Section 38 and Section 39 voluntary sector organisations



To aid more effective, person-centred assessment and intervention services for people with a range of disabilities, including autism, the HSE and WHO will work under the Collaborative Agreement on an initiative to scale, enhance and develop innovative digital and assistive technology products (DAT). This initiative will focus on the design and innovation of clinical support tools to aid clinicians.

#### Lead:

Health Service Executive

#### Supported by:

Department of Children, Equality, Disability, Integration and Youth

# 78

To support children and adults to access communication systems which meet their needs, the HSE will evaluate the impact and benefits of the Augmentative and Alternative Communication Support Programme to inform future initiatives on Augmentative and Alternative Communication.

#### Lead:

Health Service Executive

#### Supported by:

Department of Children, Equality, Disability, Integration and Youth

#### Data



To lay the groundwork for the collection of accurate data on autism, we will establish a focus group with autistic people to develop appropriate survey questions on autism.

#### Lead: National Disability Authority

#### Supported by:

Department of Children, Equality, Disability, Integration and Youth; Central Statistics Office; Health Research Board

80

To better understand existing data on autism in Ireland and methods of measuring the prevalence of autism, we will compile and analyse the strengths and weaknesses of existing datasets on autism in Ireland. We will do this in consultation with the autistic community and in line with the actions set out in the National Equality Data Strategy.

#### Lead:

National Disability Authority

#### Supported by:

Department of Children, Equality, Disability, Integration and Youth; Central Statistics Office; Health Research Board

#### Research

81

To improve our understanding of the key health challenges facing autistic people, and their associated impact on life expectancy, we will invest in research that informs policy and practice around appropriate health and social care services and supports for autistic people. This research will include a review of international literature and will be in line with the priorities of autistic people.

#### Lead:

National Disability Authority

#### Supported by:

Health Research Board; Health Service Executive



To provide a robust evidence base for neuro-affirmative practice in supporting non-speaking and minimally speaking autistic people to access public services, we will commission research to examine best practice in providing public services to non-speaking or minimally speaking autistic people. This research will be co-designed with autistic people.

Lead:

National Disability Authority



To identify best practice in supporting families and young autistic people and other young people with disabilities who have high support needs, including mental health support needs, we will conduct collaborative research with autistic people and other people with disabilities to examine:

- The nature and extent of young autistic people and young people with other disabilities facing a crisis
- The adequacy of the services and supports currently provided by the Health Service Executive and Tusla – Child and Family Agency for autistic children and young people and for children and young people with other disabilities in family crisis situations, including access to Child and Adolescent Mental Health Services, and
- The demand, availability and appropriateness of existing respite and other community services to meet their needs.

#### Lead:

National Disability Authority

# 5. Monitoring and implementation

The public consultations highlighted the importance of ensuring effective, independent oversight of, and accountability for, the delivery of actions under the Autism Innovation Strategy. This is particularly important in view of the crossgovernment nature of actions under the Strategy and the wide range of Government Departments, statutory agencies and bodies responsible for delivering them.

It is important that the monitoring and oversight framework under the Autism Innovation Strategy aligns with the broader monitoring and oversight structure of the National Disability Strategy for a number of reasons. Firstly, this will ensure coherence between the Autism Innovation Strategy (which focuses on addressing particular challenges for autistic people) and the new National Disability Strategy (which is designed to address shared challenges for all people with disabilities, including autistic people). Secondly, it will ensure that the views and lived experiences of autistic people are reflected in the stakeholder architecture and actions of the National Disability Strategy. Finally, it will ensure that autistic people are effectively supported by wider action on disability, including under the National Disability Strategy, in the future.

In recognition of the intersectional challenges facing some autistic people, it is also crucial that the implementation of actions under the Autism Innovation Strategy is informed by an awareness and understanding of the intersectional challenges that autistic people may face.

#### Autism Innovation Strategy Oversight and Advisory Group

At the centre of the oversight and monitoring architecture for the Strategy is the Autism Innovation Strategy Oversight and Advisory Group. This stakeholder group, which is majority neurodivergent, will play a key role in monitoring the implementation of the Strategy, and in providing constructive advice to guide whole-of-government work on autism based on the lived experience and expertise of group members. Group membership comprises autistic people as well as professionals, parents and representative organisations. The group was appointed in December 2022 following an application process.

After the launch of the Strategy, a group chair will be appointed and the group will meet on a quarterly basis to oversee progress in implementing the Strategy. Equally, Government Departments or statutory agencies may seek the Oversight and Advisory Group's advice to inform their delivery of particular actions under the Strategy.

To support the group in monitoring the delivery of actions, the Government Departments, statutory agencies and bodies responsible for delivering actions will provide written progress reports every 6 months. These progress reports will be compiled by the Department of Children, Equality, Disability, Integration and Youth. They will set out the progress made in delivering individual actions under the Strategy over its 18-month lifetime and will identify any delivery challenges. Fifteen months into the implementation period, outstanding actions will be identified by the Department of Children, Equality, Disability, Integration and Youth so that a particular focus can be brought to their implementation in the remaining period of the Strategy.

The reports will be provided to the Autism Innovation Strategy Oversight and Advisory Group for consideration prior to group meetings.

On the basis of the reports submitted, the group will identify specific actions that group members feel should be prioritised or discussed further. These priority actions will be escalated for discussion at Autism Innovation Strategy Steering Committee meetings.

#### **Autism Innovation Strategy Steering Committee**

The Autism Innovation Strategy Steering Committee will comprise representatives from relevant Government Departments, statutory agencies and bodies responsible for delivering actions under the Strategy. Representation will vary depending on the priority actions selected for discussion by the Oversight and Advisory Group. The Steering Committee will also comprise three representatives from the Oversight and Advisory Group: the group chair and two group members, who will speak to priority actions under the four pillars. To ensure effective accountability, the Steering Committee will be chaired by the Minister of State with special responsibility for Disability.

The Steering Committee will meet at 6-monthly intervals over the 18-month lifetime of the Strategy. The focus of Steering Committee meetings will be targeted towards discussions on the priority actions identified by the Oversight and Advisory Group.

In the event of a persistent and significant delivery issue, it is also intended that a disability senior officials group will be established under the National Disability Strategy.

#### Reporting

The Department of Children, Equality, Disability, Integration and Youth, in close cooperation with the Oversight and Advisory Group, will prepare a final report following completion of the Strategy. The report will outline the outcomes achieved under the Strategy. In this regard, it should be noted that the Strategy is designed to provide a foundation for ensuring that the needs of autistic people are better accommodated in mainstream policy and action across government. The report will therefore contain recommendations for further advancing and embedding the mainstream recognition of the needs of autistic people in the future.

# **Appendix 1**

This appendix provides additional details on the data available around autism at international and national levels. These data are summarised in Section 2: What we were told.

Based on the available data at international level, there is evidence of an increase in the number of children being identified as autistic. In the United States of America, the Centers for Disease Control and Prevention (CDC) reports that since the early 2000s, identification of autistic children aged 8 years has increased markedly, from 6.7 children per 1,000 in 2000 to 27.6 children per 1,000 in 2020. This equates to an increase from 1 in 150 children to 1 in 36 children.<sup>12</sup>

In the United Kingdom, the annual school census in England, Northern Ireland, Scotland and Wales shows a rise in the number of autistic pupils identified by schools. A longitudinal study over a 9-year period from 2010–11 to 2018–19 showed that Northern Ireland had the highest prevalence rate of autism, reaching 3.2% in 2018–19.<sup>13</sup>

More recently, the Department of Health in Northern Ireland published the *Prevalence of Autism (including Asperger Syndrome) in School Age Children in Northern Ireland Annual Report 2023*.<sup>14</sup> Using figures derived from the Northern Ireland School Census, the estimated prevalence of autism within the school-age population in Northern Ireland was 5% in 2022–23. Higher prevalence rates were found among males, in urban populations and in more socially deprived groups.

At national level, there is currently no single source of data on autism in Ireland.

Based on the range of available data, it was estimated in 2018 that autistic people represented between 1.0% and 1.5% of the Irish population.<sup>15</sup> However, drawing on international comparators and the perceived increase in the number of people being identified as autistic across a number of national sources, the number of autistic people in Ireland may be higher.

<sup>12</sup> Centers for Disease Control and Prevention (2023) Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. Available at: <u>https://www.cdc.gov/mmwr/volumes/70/ss/ss7011a1.htm</u>

<sup>13</sup> McConkey, R. (2020) 'The rise in the numbers of pupils identified by schools with autism spectrum disorder (ASD): a comparison of the four countries in the United Kingdom', *Support for Learning*, 35(2), pp. 132–143.

<sup>14</sup> Rodgers, H. and McCluney, J. (2023) *The prevalence of Autism (including Asperger Syndrome) in School Age Children in Northern Ireland Annual Report 2023.* Available at: <u>https://www.health-ni.gov.uk/publications/</u> prevalence-autism-including-aspergers-syndrome-school-age-children-northern-ireland-2023

<sup>15</sup> National Council for Special Education (2023) Annual Report 2022. Trim: National Council for Special Education.

In education settings, for example, there has been a steady increase in the number of autistic children availing of special classes and special school places, as set out in Tables 1 and 2.<sup>16</sup>

Table 1 sets out the number of special classes per year in primary schools that support autistic children. It shows the increase in the number of autism classes and autism early intervention classes in primary schools from 2010 to 2023.

Number of special classes by year – primary schools									
Class type	2010	2015	2020	2021	2022	2023			
Autism early intervention	21	71	135	133	151	157			
Autism	214	482	1,000	1,217	1,463	1,698			

 Table 1: Primary special classes supporting autistic children

Table 2 sets out the number of special classes per year in post-primary schools that support autistic children. It shows the increase in the number of autism classes in post-primary schools from 2010 to 2023.

Number of special classes by year – post-primary schools								
Class type	2010	2015	2020	2021	2022	2023		
Autism	65	189	435	524	653	780		

Most of the new provision of additional special classes and special school classes in recent years is aimed at supporting autistic children with complex needs. More than 92% of all new special classes and the majority of classes in new special schools are for autistic children. Based on preliminary data for the 2023-2024 school year, there are more than 14,500 students in autism classes in mainstream primary and post-primary schools. This represents approximately 1.5% of the overall primary and post-primary pupil population.<sup>17</sup>

<sup>16</sup> National Council for Special Education (2023) Annual Report 2022. Trim: National Council for Special Education.

<sup>17</sup> Preliminary figures from the National Council for Special Education and the Department of Education, April 2024.

In health and social care settings, with regard to the Statutory Assessment of Need process under the Disability Act 2005, there has been an increase in the number of children being identified as autistic. On average, identification of autism constituted 46% of all assessments completed by the Health Service Executive between 2015 and 2023, as shown in Table 3.

Table 3 sets out the data from assessment reports issued over the period 2015–2023, along with the percentage of autistic children.

Disability	2015	2016	2017	2018	2019	2020	2021	2022	2023	Total
Autism	582	772	955	1,163	1,220	1,645	2,169	644	1,160	10,310
Autism as	29%	38%	39%	41%	52%	63%	59%	54%	36%	46%
a percent-										
age of all										
assess-										
ments										

 Table 3: Assessment reports for 2015-2023

Data from the Health Service Executive also show that the number of autistic applicants has increased significantly among school-leavers being profiled for disability day services. Autistic applicants constituted 53% of all school-leaver applicants in 2023, as set out in Table 4.

# Table 4: Autistic school-leavers as a percentage of total school-leaver applicantsfor disability day services

Year	2018	2019	2022	2023
Number of autistic people	582	704	863	1,046
Percentage of autistic people among all applicants	N/A	35%	46%	53%

The National Ability Supports System is a national database that records information about the Health Service Executive's disability-funded services that are received or identified as required by a service provider as a result of an intellectual disability; developmental delay; physical, sensory, neurological, learning, and speech and/or language disability; or autism. Of the validated data for 2022 extracted from the National Ability Supports System database, autism was the most commonly recorded disability type for children (39%) and the fourth most frequently reported primary disability type for adults (5%).<sup>18</sup>

From the profile of autistic people engaging with disability services in 2022, overall, 15,446 people were recorded as being autistic. For 12,818 of those people, autism was recorded as their primary disability.<sup>19</sup> For the remaining 2,628 people, autism was recorded as an additional disability to their primary recorded disability. Among those, the most common primary disability reported was an intellectual disability (92%).

Among the 15,446 autistic people recorded, other key findings from the National Ability Supports System database were as follows:

- Where sex was known, 75% of those identified as autistic were male.
- Nearly four out of five (79%) were aged under 18 years.
- More than one-quarter (28%) of autistic adults were living in a residential setting. More than two-thirds (67%) of autistic adults were living with family, 4% were living alone and 1% were living with non-relatives.
- Among adults who did not reside in a residential setting, 77% reported having a primary carer.

<sup>18</sup> It is important to note that the data returned for children by the newly established Children's Disability Network Teams are less complete than the data provided by service providers for adults accessing Health Service Executive-funded disability services.

<sup>19</sup> Casey, C., Fanagan, S., O'Sullivan, M., et al. (2023) Overview of people engaging with disability services, 2022. Dublin: Health Research Board.

# **Appendix 2**

The Government Departments, statutory agencies, semi-State companies and other bodies involved in delivering on the Autism Innovation Strategy are as follows:

- Central Statistics Office (CSO)
- Citizens Information Board
- Coimisiún na Meán
- County and City Management Association
- Courts Service
- daa plc (the operator and manager of Dublin and Cork airports)
- Department of Children, Equality, Disability, Integration and Youth
- Department of Education
- Department of Education Inspectorate
- Department of Enterprise, Trade and Employment
- Department of Further and Higher Education, Research, Innovation and Science
- Department of Health
- Department of Justice
- Department of Public Expenditure, NDP Delivery and Reform
- Department of Rural and Community Development
- Department of Social Protection
- Department of Tourism, Culture, Arts, Gaeltacht, Sport and Media
- Department of Transport
- Further and higher education institutions
- Health Research Board (HRB)
- Health Service Executive (HSE)
- Health Service Executive National Office for Suicide Prevention
- Higher Education Authority (HEA)

- Intreo (the Public Employment Service)
- Irish Prison Service
- Irish Rail
- Local authorities
- Local Enterprise Offices
- Local Government Management Agency (LGMA)
- National Advocacy Service for People with Disabilities
- National Council for Special Education (NCSE)
- National cultural institutions (the National Museum of Ireland, the National Gallery of Ireland, the Irish Museum of Modern Art (IMMA), the Chester Beatty, the National Concert Hall (NCH), the Crawford Art Gallery, the National Library of Ireland (NLI), and the National Archives)
- National Disability Authority (NDA)
- National Transport Authority (NTA)
- Public Appointments Service
- Public library service
- Road Safety Authority (RSA)
- Section 38 and Section 39 voluntary sector organisations
- SOLAS
- Sport Ireland
- Sport sector organisations
- The Shannon Airport Group
- Translink
- Western Development Commission





**Rialtas na hÉireann** Government of Ireland