# Summary report on a targeted consultation with non-speaking and minimally speaking autistic people on the draft Autism Innovation Strategy

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This report was commissioned by the Department of Children, Equality, Disability, Integration and Youth (the Department), and produced by ACE Communication Ireland. Responsibility for the consultation (including any errors or omissions) remains with ACE Communication Ireland. The views and opinions contained in this report are those of the participants and do not necessarily reflect the views of the Department or ACE Communication.

We would like to thank the individuals who participated in the interviews. We thank them for their time and for sharing their views with us. We would like to thank the service providers, families, and staff members who supported us with this consultation. Finally, we would like to thank the Department for its guidance throughout the process.

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# Executive summary

## Introduction

The Department of Children, Equality, Disability, Integration and Youth (the Department) is coordinating development of a new national strategy on autism, the Autism Innovation Strategy.

An initial public consultation on the Autism Innovation Strategy was held between April and May 2022 to inform the preparation of an initial draft of the Strategy. A report analysing the submissions was published in April 2023.

The draft Autism Innovation Strategy was published in February 2024. An easy-to-read version of the draft Strategy was also published. In February 2024, a second consultation process commenced to give the autistic community and their supporters a further opportunity to have their say on the Strategy before it is finalised and launched.

As part of the second consultation, the Department commissioned ACE Communication to undertake targeted stakeholder consultations with seldom-heard groups. These targeted stakeholder consultations complemented a wider public consultation which was carried out through an online survey and written submissions.

This summary report outlines the findings of a targeted consultation with non-speaking or minimally speaking autistic people. The findings from this consultation and the wider consultation will inform the finalisation of the Autism Innovation Strategy.

The findings will be of interest to the National Disability Authority (NDA), Ministers and Government Departments, Disabled Persons Organisations, service providers, the disability community, public bodies, and other public service providers in understanding the challenges and priorities of non-speaking or minimally speaking autistic people.

## Methodology

Information was gathered for this consultation through individual interviews and written submissions. The consultation team worked with the Department to recruit participants. Information materials were prepared in easy-to-read and plain English formats (Appendices 1, 2, 3).

Individuals were given the option of participating in a face-to-face interview, participating in an online interview, or completing a written template with their responses. The interviews took place at times and venues that best suited each individual. Participants could type, write, or draw their answers onto the written template.

In total, six individual interviews were conducted. Four males and two females, aged between 18 and 65 years, took part in the consultation. The participants were from counties Donegal, Dublin, Mayo, and Wicklow. Three individuals were non-speaking and three were minimally speaking. Some of the participants also had an intellectual disability.

The participants were supported in expressing their views and sharing their experiences through a number of different approaches, including:

- Completing a Talking Mat[1] to show which actions are most important to them (see Appendix 4 for sample Talking Mat)
- Sharing their person-centred plan[2] containing their dreams, wishes, and goals
- Sharing their communication passport[3] containing information about their interests, preferences, and communication support needs
- Using visual supports such as photos, symbols, and drawings
- Using Augmentative and Alternative Communication (AAC): for example, visual supports such as photos and symbols, Lámh sign language, or communication devices
- Using a written template to answer the consultation questions
- Being helped by family and staff members.

The consultation team followed best practice in consulting with autistic people and people with intellectual disabilities, and observed the maintenance of ethical standards. Consent to participate was considered an ongoing process.

The consultation team developed a topic guide for the interviews in collaboration with the Department. This was based on the broad themes and questions raised in the online survey. The topic guide acted as a framework for the discussions. The key questions were as follows:

- What do you think of the draft Autism Innovation Strategy?
- What areas under the Strategy are important to you in your daily life?
- What three actions are most important to you?

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[1] A Talking Mat is a visual communication framework which supports people in expressing their feelings and views: see www.talkingmats.com for more information.

[2] Person-centred planning supports and enables a person in making informed choices about how they want to live their life, both now and in the future. It supports the person in identifying their dreams, wishes, and goals, and what is required to make those possible (HSE (2018) *The National Framework for Person-Centred Planning in Services for Persons with a Disability*. Available at: https://www.hse.ie/eng/services/list/4/disability/newdirections/person-centred-planning-framework-report.pdf)

[3] A communication passport is a practical and person-centred way to pass on key information about people with different communication needs who cannot easily speak for themselves.

- What challenges or barriers do you face as an autistic person in Ireland?
- What challenges or barriers do you face as a non-speaking or minimally speaking autistic person in Ireland?
- What do you think people should know about autism?
- What three messages would you like to see included in a public campaign about autism?

The questions were adapted to suit each individual. The data collected was stored securely and in line with data protection and storage policies.

## The most important actions in the draft Autism Innovation Strategy

There are four pillars in the draft Autism Innovation Strategy. The information gathered was organised under each of these pillars.

The importance of listening to autistic people and their families was a strong theme across the interviews. One participant highlighted the importance of listening to the views of non-speaking or minimally speaking autistic people:

> “For too long non-speakers have been ignored, passed over, disregarded and even not consulted about so many aspects of their daily lives, for example about the types of supports they need to achieve their potential, and about their plans and hopes for their futures.”

The actions in Pillar 2 (Equality of access to public services) and Pillar 4 (Building capacity and self-advocacy) were particularly important to the participants in this consultation. Under each pillar, participants identified the following actions as important to them:

### Pillar 1: Autism-affirming society

- We will have a campaign to help the public understand autism. Autistic people will help to design this campaign.
- We will support an autism training programme for staff working with autistic people. This will be for staff in the Health Service Executive (HSE) and health and social care organisations.
- We want public services to be autism friendly. We will have a new e-learning course to help staff in the public sector learn about autism and other disabilities.

### Pillar 2: Equal access to public services

- We will show that the needs of autistic people are part of Universal Design.

- We will support plans for learning places that make everyone feel welcome and included.
- We will look at supports for autistic people to take part in further and higher education.
- We will support access to health and social care services for autistic people.
- We will roll out our plan for better access to disability services. We will make disability services more person-centred.
- We will support autistic children and adults to get the right mental health services.
- We will work to have better therapy supports for autistic children.
- We will make sure that information is clear and accessible, for example, information on autism services and supports.
- We will have actions to make sure that autistic people can use different types of transport.

### Pillar 3: Accessible, inclusive communities

- We want cultural places to be accessible and autism friendly, such as museums and galleries.
- We will support autistic people to use public libraries. We will think about the needs of autistic people when we design public libraries.
- We will make sure that autistic people are supported and have a chance to take part in sport.

### Pillar 4: Building capacity and self-advocacy

- We will research the best ways to give public services to autistic people who do not speak.
- We will do research with autistic people to look at services for people who need emergency supports and respite services.

### What the public need to know about autism

The participants in this element of the consultation focused on key messages that would raise awareness of autism, promote acceptance, support autistic people in interacting with a wider circle of people, increase their independence, and facilitate them in engaging more in their preferred activities in their communities. Supporters assisted them in translating their goals, preferences, experiences, and the information in their personal profiles into individual messages that might form part of a public campaign.

## Conclusion

It is very important to include individuals who communicate in different ways in the consultation process. However, it should be noted that, in order to do this meaningfully, the approach taken and the time frame set must be flexible in order to ensure that each person can engage fully and that the experience is a positive one for them.

Participants welcomed the opportunity to be involved in this consultation. They had limited or no previous experience of taking part in similar consultations but were eager to share their experiences to inform the Strategy. They actively engaged in the different approaches provided that supported them in doing this, sharing valuable views and ideas.

# 1. Introduction

The Department of Children, Equality, Disability, Integration and Youth (the Department) has responsibility for the development of disability equality policy and legislation. The *Programme for Government: Our Shared Future* contains a commitment to action on autism. The Department is coordinating development of a new national strategy on autism, the Autism Innovation Strategy.

The Autism Innovation Strategy aims to address the unique challenges and barriers facing autistic people, and to improve understanding and accommodation of autism in society and across the public sector. The Autism Innovation Strategy contains actions that will be undertaken across government to better support autistic people and their families over an 18-month period. The Autism Innovation Strategy will complement and enhance wider reform efforts by focusing on areas where unique challenges arise for autistic people.

An initial public consultation on the Autism Innovation Strategy took place between April and May 2022 to inform the preparation of an initial draft of the Strategy. A report analysing the submissions was published in April 2023.

The draft Autism Innovation Strategy was published in February 2024. An easy-to-read version of the draft Strategy was also published. In February 2024, a second consultation process commenced in order to give the autistic community and their supporters a further opportunity to have their say on the Strategy before it is finalised and launched.

As part of the second consultation, the Department commissioned ACE Communication to undertake targeted stakeholder consultations with seldom-heard groups, in recognition of the specific needs and views of different cohorts and the need to ensure the widest possible reach of the consultation. These targeted stakeholder consultations complemented a wider public consultation, which was carried out through a survey and written submissions.

This summary report outlines the findings of the targeted consultation with non-speaking or minimally speaking autistic people. This consultation provided an opportunity for six individuals to voice their lived experience, talk about the barriers and challenges they face, identify the actions from the draft Strategy that are most important to their lives, and put forward ideas for improving the lives of autistic people in Ireland. The findings from this targeted consultation and the wider consultation will inform the finalisation of the Autism Innovation Strategy.

The findings will be of interest to the National Disability Authority (NDA), Ministers and Government Departments, Disabled Persons Organisations, service providers, the disability community, public bodies, and other public service providers in understanding the challenges and priorities of non-speaking or minimally speaking autistic people.

# 2. Methodology

## 2.1 Recruitment

Information was gathered for this consultation through individual interviews and written submissions. The consultation team worked with the Department to recruit participants. Collaboratively, contact was made with a number of service providers and parents to explain the nature of the consultation and seek their support.

The consultation team worked with a small group of experts with lived experience to create an information leaflet in easy-to-read and plain English formats, as well as an expression of interest form (Appendices 1, 2, 3).

If necessary, staff or family members supported the person in reviewing the consultation information and completing the expression of interest. Details about the interviews were communicated to each person via staff or parents. The interviews took place at times and venues that best suited each individual. A template was emailed to those who preferred to respond with a written submission.

## 2.2 Sample size and participant profile

The Department and ACE Communication agreed to use a sample size of five to six autistic people at the outset of this targeted consultation. The aim was to include individuals of different ages, living in both rural and urban settings.

In total, six people took part. Four interviews were conducted face to face and one online. One participant sent a written submission. The participants were from counties Dublin, Donegal, Wicklow, and Mayo. Three individuals were non-speaking and three were minimally speaking. Some of the participants also had an intellectual disability. Four lived at home with their family and two lived in residential community houses.

The age and gender of the participants are outlined in Table 2.1 below.

**Table 2.1 Age range of participants**

| Age range | Male | Female | Total number of participants |
|---|---:|---:|---:|
| 18–30 years | 2 | 1 | **3** |
| 31–50 years | 1 | 0 | **1** |
| 50+ years | 1 | 1 | **2** |
| **Total** | **4** | **2** | **6** |

## 2.3. Consent

The consultation team followed best practice in consulting with autistic people and people with intellectual disabilities, and observed the maintenance of ethical standards.

The information materials on the consultation process were designed to ensure that participants:

- Understood what the consultation was about
- Understood key information about the interview or written submission
- Were aware that they had a choice to participate or not
- Understood that they could change their minds at any time.

The individuals, and their supporters, were given the opportunity to review the consultation information, to ask questions, and to contact the lead facilitator prior to the interview. Consent to participate was considered an ongoing process. The facilitator's observations of each person's verbal and non-verbal communication, along with the observations of staff present, guided the team on the consent of the person to participate.

The consultation team and the Department were aware from the outset that the time frame and approach would need to be flexible in order to ensure that the team could support non-speaking or minimally speaking individuals in engaging meaningfully in this process. If there was any doubt about a person's consent to participate, they were not included. Three people were nominated to participate in this consultation, and they expressed an interest in doing so. However, on the day of the interview, they did not feel ready to take part for different reasons. An alternative date was arranged for two of these individuals, and one person turned down an alternative time.

At the start of each interview, the facilitator checked to ensure that each person still wished to take part. Participants were advised that they could take a break or leave the interview at any time.

## 2.4. Information gathering

The consultation team developed a topic guide for the interviews and written submissions in collaboration with the Department. This was based on the broad themes and questions raised in the online survey on the draft Autism Innovation Strategy.

The topic guide acted as a framework for the discussions. The key questions for the interviews were as follows:

- What do you think of the draft Autism Innovation Strategy?
- What areas under the strategy are important to you in your daily life?

- What three actions are most important to you?
- What challenges or barriers do you face as an autistic person in Ireland?
- What challenges and barriers do you face as a non-speaking or minimally speaking autistic person in Ireland?
- What do you think people should know about autism?
- What three messages would you like to see included in a public campaign about autism?

The questions were adapted to suit each individual.

The duration of each interview was between 30 and 90 minutes. In all interviews, a staff or family member sat in to provide extra support for the participant.

Participants were well supported by staff and their family members in engaging in this consultation. Participants' experiences and views were central to each interview, even when they needed assistance from others to make themselves understood. Supporters refrained from giving their own opinions, and instead focused on the views of the participant.

Participants shared their views and responded to questions in a number of different ways:

- Completing a Talking Mat[4] to show which actions are most important to them (see Appendix 4 for sample Talking Mat)
- Sharing their person-centred plan[5] containing their dreams, wishes, and goals
- Sharing their communication passport[6] containing information about their interests, preferences, and communication support needs
- Using visual supports, such as photos, symbols, and drawings
- Using Augmentative and Alternative Communication (AAC): for example, visual supports such as photos and symbols, Lámh sign language, or communication devices
- Using a written template to answer the consultation questions

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[4] A Talking Mat is a visual communication framework which supports people in expressing their feelings and views: see www.talkingmats.com for more information.

[5] Person-centred planning supports and enables a person in making informed choices about how they want to live their life, both now and in the future. It supports the person in identifying their dreams, wishes, and goals, and what is required to make those possible (HSE (2018) *The National Framework for Person-Centred Planning in Services for Persons with a Disability*. Available at: https://www.hse.ie/eng/services/list/4/disability/newdirections/person-centred-planning-framework-report.pdf)

[6] A communication passport is a practical and person-centred way to pass on key information about people with different communication needs who cannot easily speak for themselves.

- Being helped by family and staff members

The easy-to-read version of the Autism Innovation Strategy was used as the focus for the interviews and the basis for the Talking Mats. It was provided to each individual and their supporters in advance of the interview. Participants were also directed to the main Strategy report so they could use this if they preferred.

The data collected consisted of written notes and submissions, photographs, and memory-based analysis. All data from the project were stored securely and in a way that was in line with data protection and storage policies.

Personal or other identifiers are not used in this report. Codes were used to identify participants during the data analysis. The coding information was stored separately from the data and destroyed once the analysis was completed. Notes were prepared by a research assistant and double-checked by the lead facilitator to ensure that no identifying information was present.

The data were organised and coded manually. The key findings were collated and summarised.

# 3. The most important actions in the draft Autism Innovation Strategy

It was not possible to address all actions in the draft Autism Innovation Strategy during the interviews or in the written submissions. The facilitator selected a number of relevant areas and actions and presented these for discussion and consideration. In addition, participants and their supporters raised issues and actions of importance to them.

There are four pillars in the draft Autism Innovation Strategy. The information discussed was organised under each of these pillars to identify the actions which this group considered to be the highest priority. There was some different views across the six participants which reflected their ages, living situations, personal interests, and lived experience. One participant explained that priorities change over time as needs and circumstances change.

The importance of listening to autistic people and their families was a strong theme across the interviews and submissions. One participant highlighted in particular the importance of listening to the views of non-speaking or minimally speaking autistic people.

> “For too long non-speakers have been ignored, passed over, disregarded and even not consulted about so many aspects of their daily lives, for example about the types of supports they need to achieve their potential, and about their plans and hopes for their futures.”

## 3.1 Pillar 1: Autism-affirming society

Under this pillar, participants identified the following actions as important:

- **We will have a campaign to help the public understand autism. Autistic people will help to design this campaign.**

Participants and their supporters identified some of the challenges they face due to the public’s lack of understanding about autism. Examples included being treated like a child because you communicate differently; not being given time to process information; a lack of accessible information; inaccessible and/or cluttered environments; a lack of sensory or quiet spaces; being shown disrespect; and a lack of understanding of ‘stimming’.

One participant highlighted three key elements to a more inclusive society for autistic people:

“Acceptance. Respect our intelligence. Support our different methods of communication.”

Supporters suggested that stereotypes of autism can be very damaging, and sometimes the public can respond negatively to requests for support when an autistic person is feeling ‘overwhelmed’, ‘anxious’, or ‘communicating their distress through behaviour’.

- **We will support an autism training programme for staff working with autistic people. This will be for staff in the Health Service Executive (HSE) and health and social care organisations.**

The majority of participants noted the importance of ‘good’ staff. They noted that ‘good’ staff support them in achieving their personal goals and taking part in their communities. These staff members understand them well and recognise their skills and needs. Participants mentioned the ‘key worker’ system under this action as a vital support for autistic individuals with communication support needs.

Overall, participants welcomed additional training for staff working with autistic people, and two individuals suggested that it should include education around different communication tools and approaches.

- **We want public services to be autism friendly. We will have a new e-learning course to help staff in the public sector learn about autism and other disabilities.**

Participants communicated a strong desire for public services in their communities to be autism friendly. For example, by making their buildings more accessible; by learning about and understanding different communication methods; and by understanding and having a positive attitude towards autism.

Participants and their supporters described some of the communication challenges they face when using public services and said that they would welcome any improvement to this. Supporters highlighted the need for public services to understand the different support needs an autistic person may have, for example, in relation to communication or behaviour.

### 3.2. Pillar 2: Equal access to public services

- **We will show that the needs of autistic people are part of Universal Design.**

Participants said that they use a wide range of places and services in their local communities, including shops, restaurants, cinemas, parks, leisure centres, beaches, and public buildings. It was particularly important for this group that such places follow practices of Universal Design.

Some of the participants had additional mobility needs. All of the participants referred to their sensory needs in public places. Key challenges included noisy environments; busy places where people are too close together; long queues; overly cluttered spaces; lack of light or fresh air; smells; lack of accessible toilets; and lack of accessible parking spaces.

In addition, two individuals commented on the need for day service buildings to be better designed to meet the needs of autistic people.

One participant explained that Universal Design is key to enabling independence and control for autistic people.

- **We will support plans for learning places that make everyone feel welcome and included.**

Two of the participants had experienced attending education centres outside of their day or residential service. They enjoyed this and would like to explore this further in the future.

One participant explained that appropriate supports are needed to ensure that autistic children and young people have access to education “from diagnosis, through primary and secondary school, with autism-specific individual accommodations for state exams, and intensive specific support at third level”. They recommended that children and young people have access to “appropriate education placements, based on the needs of the individual student, rather than a ‘one-size-fits-all’ and a ‘take-what-you-can-get’ approach”.

- **We will look at supports for autistic people to take part in further and higher education.**

Some of the participants are completing Quality and Qualifications Ireland (QQI) education modules within their day service. One person is engaging in a course in their community. They expressed an interest in learning new things and would like more opportunities to do this as well as to pursue their current areas of interest. Examples of their interests include gardening, art, pottery, mindfulness, Tai Chi, yoga, walking, nature, and music.

One participant is completing a third-level qualification. They highlighted some of the challenges they face in this setting.

> “I have proven my ability, with first-class honours to date in all subjects, but I struggle with some aspects of the course, and it is unknown territory for both me and my very patient lecturers!”

While participants expressed a strong interest in education and lifelong learning, they had little interest in employment or vocational training. This may be related to people’s lived experience and expectations, or to the demands they believe employment would place on them.

> “Employment is not really an option for someone like me, at least not in the traditional sense, but I would like to earn my own money.”

- **We will support access to health and social care services for autistic people.**

The majority of the participants are users of day services. Two live in residential houses. Two of the four people living at home use a respite service. The participants said that these services are very important to them and support them in having a good quality of life.

Two individuals highlighted the lack of access to multidisciplinary supports, in particular to physiotherapy and occupational therapy.

One participant highlighted the challenges that autistic people face in accessing public health services.

> “Health services have always let me down. My Mam was once asked ‘what was wrong with me’ when I couldn’t sit still for an eye exam, and we have paid for a private dentist on numerous occasions as there was a two-year wait for the special needs dentist, even though I had an open abscess and was in severe pain. Luckily I am generally healthy, but there are so many others who need understanding health services, delivered quickly, before problems escalate, leading to behaviour problems and exclusion from the activities we love.”

- **We will support autistic children and adults to get the right mental health services.**

One person communicated the importance of regular psychological supports to their well-being. They received this through their service provider. Some participants were supported by family or staff in actively engaging in activities and supports for their mental well-being: for example, yoga, mindfulness, Tai Chi, swimming, and spending time in nature.

Two individuals explained that when they feel anxious or stressed they are able to talk to staff, a psychologist, or a psychiatrist. Other individuals did not have any access to professional support from mental health services but would like to have this available should they need it.

- **We will work to have better therapy supports for autistic children.**

One participant highlighted the need for early diagnosis and intervention and better access to therapy supports for autistic children.

> “A strategy is a plan, and for most of my life there has been very little planning, even though I was diagnosed at a young age. Early diagnosis supported by early intervention is a priority, with services such as speech, occupational, behaviour therapies, and in my case AAC [Augmentative and Alternative Communication], guaranteed…My needs and my progress changed over the years, and I would have benefitted by regular reviews, and from the professionals who appeared mainly in response to a crisis situation actually sitting down with me and my parents and listening to our experiences, and providing support in the areas we identified and needed.”

While mostly welcoming the input of professionals, some participants and their supporters expressed frustration at current models of therapy provision and the lack of consistent support for children and adults. They would like to see more dialogue between professionals, autistic people, and their families about the types of services and supports they require.

- **We will roll out our plan for better access to disability services. We will make disability services more person-centred.**

The main focus of discussion on this action were person-centred plans and personal goals. The participants wanted their disability service to support them in setting and achieving their goals, and in living the life they want. They highlighted the importance of making their own choices and decisions, and of having access to individualised supports rather than group activities.

- **We will make sure that information is clear and accessible, for example, information on autism services and supports.**

Two of the participants had literacy skills. The others rely on information in accessible formats to get information and make decisions, such as visual supports, easy-to-read information, videos, radio, and television (TV) shows. They would like to see more information available in these formats, particularly video information.

- **We will have actions to make sure that autistic people can use different types of transport.**

Participants from rural settings highlighted the challenge of limited public transport options in rural and remote areas. They also highlighted limited transport options in day and residential services as a significant barrier to autistic people taking part in their communities.

Some of the participants avoid public transport because it is too busy, smelly, and unreliable. Others explained that they can only use public transport if there is a person to support them. Two participants expressed a desire to use public transport independently and to have more travel training to facilitate this. They praised the service offered by Dublin Bus and would like to see more initiatives like this. Supporters suggested that staff on public transport might benefit from autism awareness training.

## 3.3. Pillar 3: Accessible, inclusive communities

- **We want cultural places to be accessible and autism friendly, such as museums and galleries.**

Four of the six participants said they would like to visit more cultural places. They would like these to be as interactive as possible. They would like information in accessible formats.

Quiet spaces would be very welcome in these locations. Supporters noted the importance of autism-friendly events and performances in venues such as cinemas and theatres.

- **We will support autistic people to use public libraries. We will think about the needs of autistic people when we design public libraries.**

Some participants were interested in using the public library and some were not. Two people had no experience of visiting a library but expressed a desire to do so.

One participant said they would like libraries to stock photo or picture books which are appropriate for adults. They also said they would like to learn to use the computers in the library, or to go to classes there.

Most participants supported the idea of quiet rooms and sensory rooms in the library. One participant with mobility difficulties explained that a new library near their home is very easy to get into and around.

- **We will make sure that autistic people are supported and have a chance to take part in sport.**

Some participants are already actively engaged in both individual and inclusive sports. They expressed a desire to continue this and to try new sports and types of exercise. One participant explained that they do not participate in sport but love to watch sports events, both live and on TV. They would like to see autistic people encouraged to attend and welcomed at sporting events and local sports clubs, such as GAA clubs. Some participants noted that you should be able to do this as a supporter if you do not want to play. You may be able to offer alternative skills to these clubs and associations: for example, one participant suggested helping in a club shop or café.

### 3.4. Pillar 4: Building capacity and self-advocacy

One participant identified Pillar 4 as being "very important to my future". They noted the significance of technology and research for autistic people who are non-speaking or minimally speaking.

> "I hope that current research findings into the hidden and linguistic abilities of non-speaking autistics will break down the barriers that I face as an autistic person in Ireland today."

- **We will research the best ways to give public services to autistic people who do not speak.**

All the participants reported using public services. They had all experienced some challenges and said they would like to be able to use these services more independently. They welcomed the idea of exploring the needs of non-speaking autistic people. The participants had ideas for positive changes to public services, including: more video information; printed information in formats that better suit autistic people (for example, printed on off-white matt paper and using particular fonts); representation of autistic people in images; and use of Augmentative and Alternative Communication.

- **We will do research with autistic people to look at services for people who need emergency supports and respite services.**

Some of the participants use respite services regularly. They were very happy with these services and reported enjoying their stays. They would like more respite if possible, and different models of respite: for example, short breaks, respite in different locations, and more individual supports.

### 3.5. Priority actions

Each participant was asked to select three actions or issues that they would most like to see progress on. Their responses were as follows:

**Participant 1 – male in his 60s**

- We will make sure that autistic people are supported and have a chance to take part in sport.
- We will do research with autistic people to look at services for people who need emergency supports and respite services.
- We will roll out our plan for better access to disability services. We will make disability services more person-centred.

**Participant 2 – female in her 20s**

- We will look at supports for autistic people to take part in further and higher education.
- We will make sure that autistic people are supported and have a chance to take part in sport.
- We will show that the needs of autistic people are part of Universal Design.

**Participant 3 – male in his 40s**

- We will look at supports for autistic people to take part in further and higher education.
- We will support autistic people to use public libraries. We will think about the needs of autistic people when we design public libraries.
- We will support an autism training programme for staff working with autistic people. This will be for staff in the HSE and health and social care organisations.

**Participant 4 – female in her 60s**

- We will support an autism training programme for staff working with autistic people. This will be for staff in the HSE and health and social care organisations.
- We will support autistic children and adults to get the right mental health services.
- This participant would like to see more actions on communication supports for autistic people.

**Participant 5 – young male adult**

- We will support an autism training programme for staff working with autistic people. This will be for staff in the Health Service Executive and health and social care organisations.
- We will show that the needs of autistic people are part of Universal Design.
- We will have a campaign to help the public understand autism. Autistic people will help to design this campaign.

**Participant 6 – young male adult**

- We will look at supports for autistic people to take part in further and higher education.
- We will research the best ways to give public services to autistic people who do not speak.
- We will have a campaign to help the public understand autism. Autistic people will help to design this campaign.

# 4. What the public need to know about autism

Some participants found this question a little abstract, and some needed assistance from their supporters to identify key messages for a public campaign. A few participants used their person-centred plan or communication passport to explain the challenges they encounter and the supports they need. For others, the key messages emerged as they developed their Talking Mat, through discussion of the different areas and actions in the draft Autism Innovation Strategy.

Two participants and their supporters expressed frustration at the stereotypes of autism, explaining that these promote misunderstanding, low or unrealistic expectations of what autistic people are capable of, and blasé attitudes towards autism.

One participant emphasised that “awareness is not enough, let’s strive for acceptance”.

Supporters suggested that a public campaign should focus on human rights; on practical things that the public can do to support autistic people; and generally on increasing awareness of autism. It should promote tolerance and diversity in all aspects of life.

Participants agreed that a public campaign should be designed and led by autistic people, and it should feature autistic people and their friends, family members, and others who are important in their lives. Everyone agreed that the campaign should feature autistic people who are non-speaking or minimally speaking and should highlight the many forms of communication that autistic people use.

The following messages reflect the views of the participants and summarise their ideas for key messaging in a public campaign about autism:

- “I see things differently to you. Try to put yourself in my shoes and see things from my side.”
- “We listen and understand, we have feelings and opinions and valuable insights to share from our unique view of the world.”
- “Just because I do not speak doesn’t mean I have nothing to say or I don’t understand.”
- “Understand that we are intelligent; non-speaking doesn’t mean non-thinking.”
- “I want to talk to people, but you need to learn my way of talking.”
- “I can make my own choices and decisions even though I do not speak.”
- “Don’t speak about us as if we can’t hear, don’t make decisions for us without asking us, don’t exclude us when we have episodes where we can’t control our behaviours or sensory issues. They might make you uncomfortable, or embarrass you, but they are part of who we are, the fabric of our autistic lives.”

- “Don’t rush me. Give me time to process information, react, and respond.”
- “I want to do things in my own time.”
- “Give me personal space. I don’t like people I don’t know in my personal space.”
- “Ask before you touch me. Sometimes, I don’t like being touched.”
- “It might take me some time to get to know you, to respond to you, and decide if I like you.”
- “Everybody should be treated with respect.”
- “Treat me like an adult not a child.”
- “I do not like change.”
- “I am autistic, but I like new experiences and to try out new places. Everyone is different.”
- “We are all individuals.”
- “I have important goals that I want to achieve in my life.”
- “I need buildings and places to be accessible so I can be as independent as possible.”
- “I am autistic, but I am very social and like to be with people.”
- “There are some things that are very important to me that might seem silly to you. Respect my likes and preferences.”
- “I only eat certain food. Please don’t try to make me eat food that I do not like.”
- “Sometimes I may tell you I am upset or unhappy through my behaviour.”
- “When I walk into you, it is because I am focused on getting to something else. I do not mean to ignore or hurt you.”
- “Try to understand what it is like to feel overwhelmed and anxious with your head spinning with too much information.”
- “Sometimes I just need space to ‘switch out’ and relax. It might look like I am doing nothing, but I am giving my brain a rest.”
- “I am very happy most of the time.”
- “I love to learn.”
- “I have built some strong relationships and friendships, and I can be very affectionate with the people I love.”

# 5. Conclusion

It is very important to include individuals who communicate in different ways in the consultation process. However, it should be noted that to do this meaningfully, the approach taken and the time frame set must be flexible in order to ensure that each person can engage fully and that the experience is a positive one for them.

Participants were well supported by their family and staff members in engaging in this consultation. Their experiences and views were central to each interview even when they needed assistance from others to make themselves understood. Supporters refrained from giving their own opinions, and instead focused on the views of the participant.

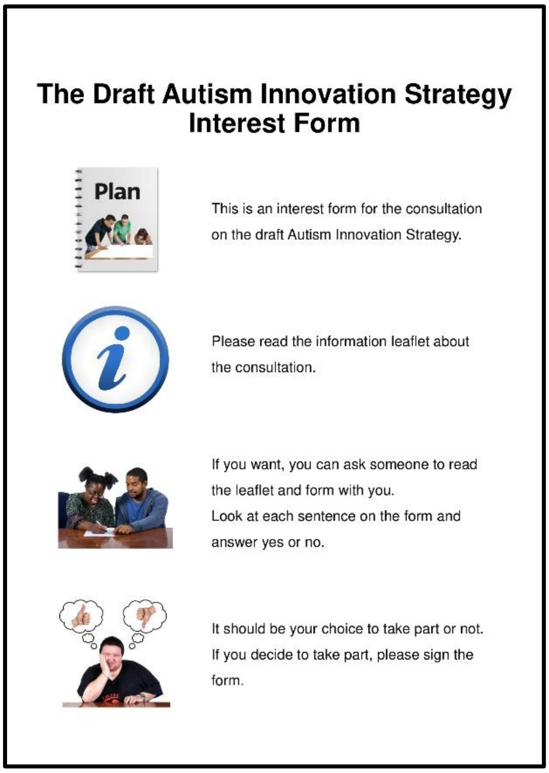
Overall, participants welcomed the opportunity to be involved in this consultation. Most had limited or no experience of taking part in consultations but were eager to share their insights and experiences. They actively engaged in the different methodologies that supported them in doing this, sharing valuable views and ideas. They clearly identified areas and actions of priority for them, and they suggested key messages for a public campaign about autism.

> “Thank you for this opportunity to contribute to the consultation on the Autism Innovation Strategy. Thank you for including the voice of non-speakers like myself…Please make this strategy a plan going forward, to a better future where autistic people like me have the same rights and opportunities as my non-autistic peers.”

Participants and supporters emphasised the need for different Government Departments to work collaboratively on the actions in the Autism Innovation Strategy.  They recommended that Government Departments “listen to the voice of the person and their families. Nothing about us without us please”.

# 6. Appendices

## Appendix 1 – Expression of interest form



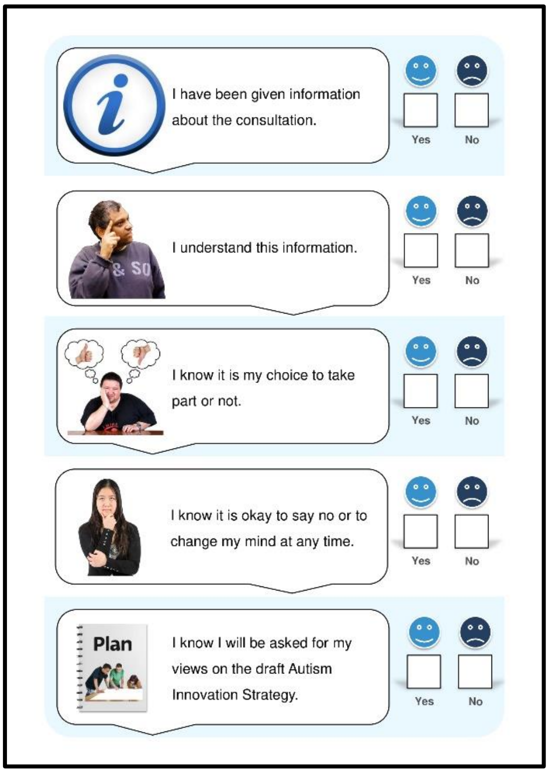
### The Draft Autism Innovation Strategy Interest Form

This is an interest form for the consultation on the draft Autism Innovation Strategy.

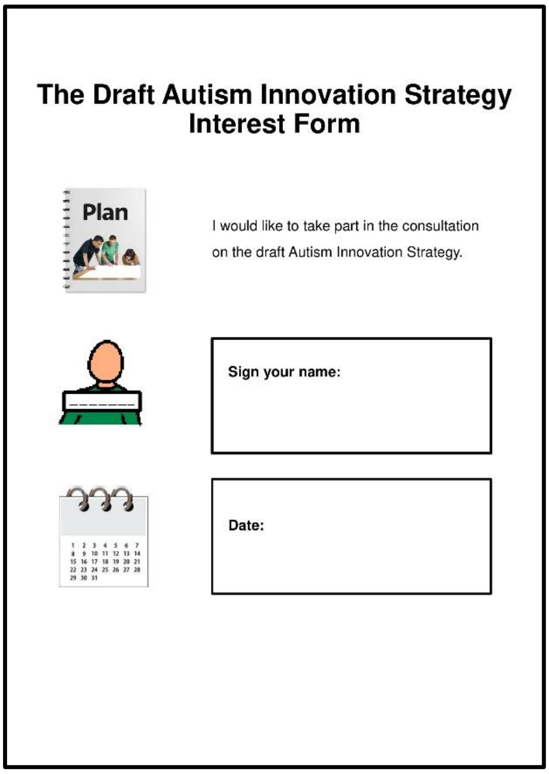
Please read the information leaflet about the consultation.

If you want, you can ask someone to read the leaflet and form with you.
Look at each sentence on the form and answer yes or no.

It should be your choice to take part or not.
If you decide to take part, please sign the form.



| | | |
|---|---|---|
| I have been given information about the consultation. | ☐ Yes | ☐ No |
| I understand this information. | ☐ Yes | ☐ No |
| I know it is my choice to take part or not. | ☐ Yes | ☐ No |
| I know it is okay to say no or to change my mind at any time. | ☐ Yes | ☐ No |
| I know I will be asked for my views on the draft Autism Innovation Strategy. | ☐ Yes | ☐ No |



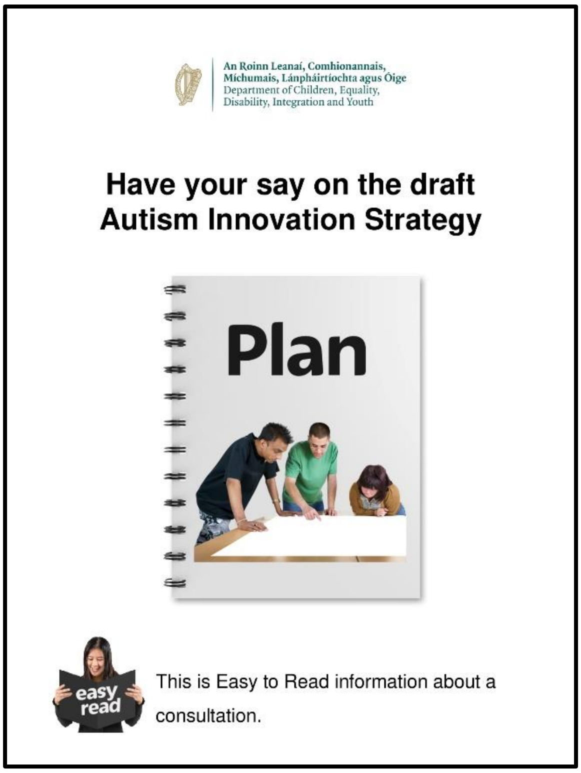
### The Draft Autism Innovation Strategy Interest Form

I would like to take part in the consultation on the draft Autism Innovation Strategy.

**Sign your name:**

**Date:**

## Appendix 2 – Easy-to-read information leaflet



An Roinn Leanaí, Comhionannais, Míchumais, Lánpháirtíochta agus Óige
Department of Children, Equality, Disability, Integration and Youth

**Have your say on the draft Autism Innovation Strategy**

This is Easy to Read information about a consultation.

**What is the Draft Autism Innovation Strategy?**

| | |
|---|---|
| Plan | The draft Autism Innovation Strategy is a plan.<br>Draft means that the plan can change. |
| | This plan is about making good changes for autistic people and their families in Ireland. |
| | We want autistic people to have the same rights as everyone else. |
| | We want autistic people to be able to live the life they choose. |

1

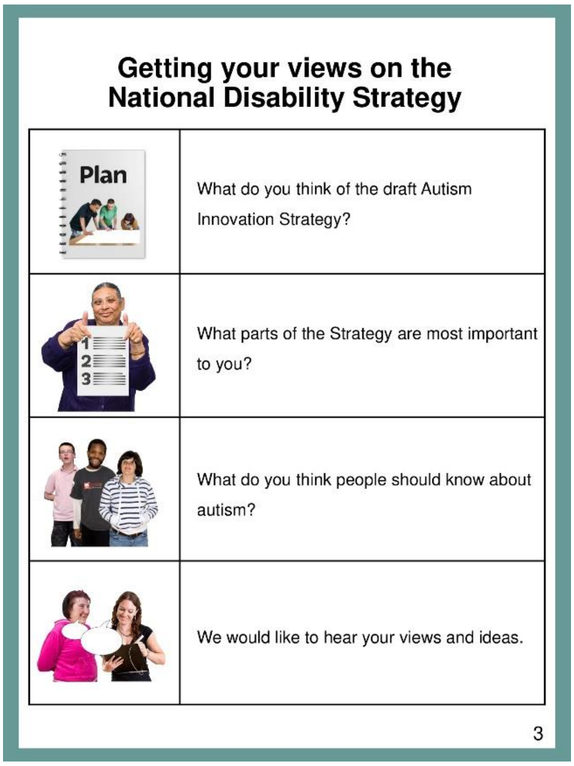
## What is the Draft Autism Innovation Strategy?

The Department of Children, Equality, Disability, Integration and Youth are putting this Strategy together.

This information leaflet is about a consultation.

A consultation is when you ask people for their views.

The Department would like to hear what autistic people think about the draft Autism Innovation Strategy.



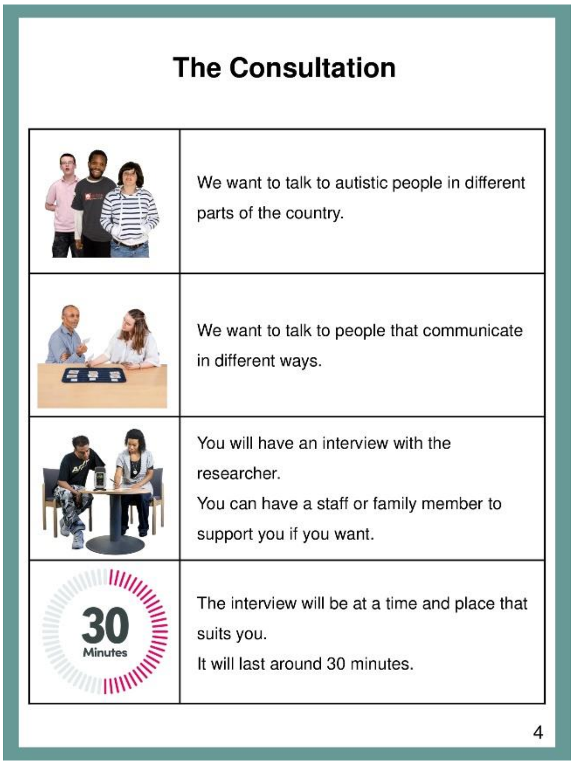
## Getting your views on the National Disability Strategy

What do you think of the draft Autism Innovation Strategy?

What parts of the Strategy are most important to you?

What do you think people should know about autism?

We would like to hear your views and ideas.



## The Consultation

We want to talk to autistic people in different parts of the country.

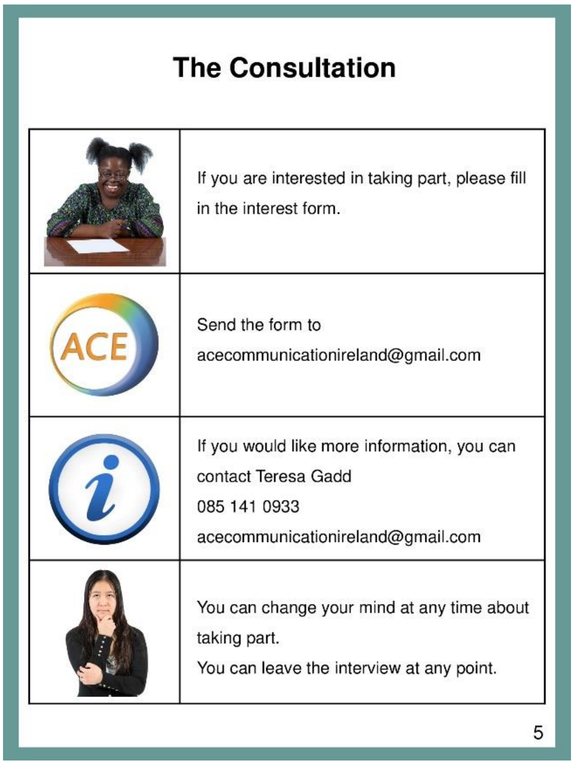
We want to talk to people that communicate in different ways.

You will have an interview with the researcher.

You can have a staff or family member to support you if you want.

The interview will be at a time and place that suits you.

It will last around 30 minutes.



## The Consultation

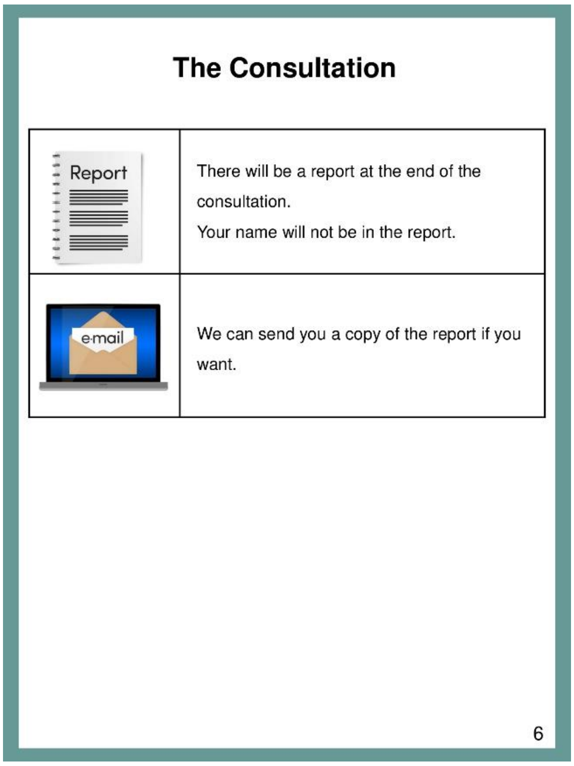
If you are interested in taking part, please fill in the interest form.

Send the form to acecommunicationireland@gmail.com

If you would like more information, you can contact Teresa Gadd
085 141 0933
acecommunicationireland@gmail.com

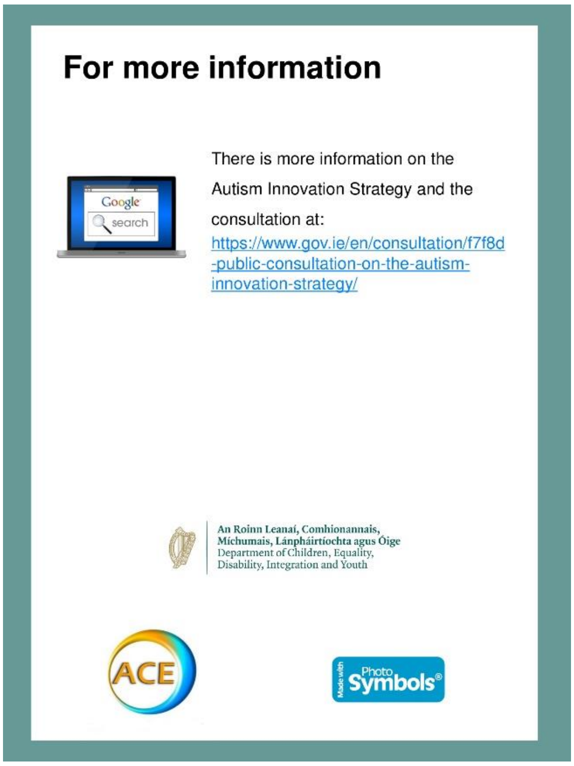
You can change your mind at any time about taking part.

You can leave the interview at any point.



## The Consultation

| | |
|---|---|
| Report | There will be a report at the end of the consultation.<br>Your name will not be in the report. |
| e-mail | We can send you a copy of the report if you want. |



## For more information

There is more information on the Autism Innovation Strategy and the consultation at: https://www.gov.ie/en/consultation/f7f8d-public-consultation-on-the-autism-innovation-strategy/

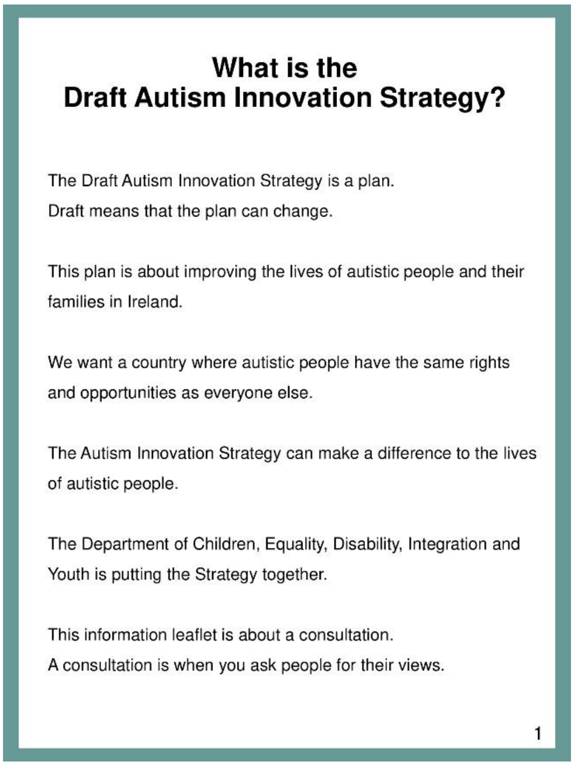
An Roinn Leanaí, Comhionannais, Míchumais, Lánpháirtíochta agus Óige
Department of Children, Equality, Disability, Integration and Youth

## Appendix 3 – Plain English information leaflet

An Roinn Leanaí, Comhionannais,
Míchumais, Lánpháirtíochta agus Óige
Department of Children, Equality,
Disability, Integration and Youth

**Have your say on the Draft Autism Innovation Strategy**

This is Plain English information about a consultation.



**What is the Draft Autism Innovation Strategy?**

The Draft Autism Innovation Strategy is a plan.
Draft means that the plan can change.

This plan is about improving the lives of autistic people and their families in Ireland.

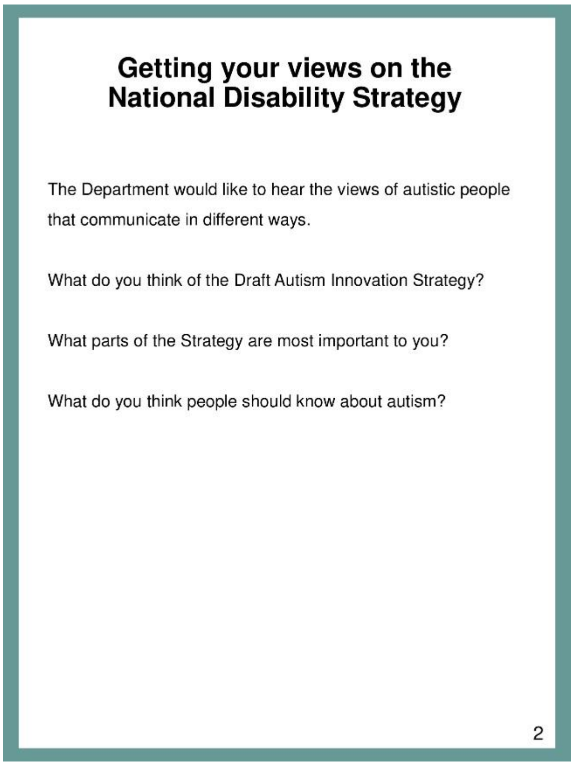
We want a country where autistic people have the same rights and opportunities as everyone else.

The Autism Innovation Strategy can make a difference to the lives of autistic people.

The Department of Children, Equality, Disability, Integration and Youth is putting the Strategy together.

This information leaflet is about a consultation.
A consultation is when you ask people for their views.

1



**Getting your views on the National Disability Strategy**

The Department would like to hear the views of autistic people that communicate in different ways.

What do you think of the Draft Autism Innovation Strategy?

What parts of the Strategy are most important to you?

What do you think people should know about autism?

2

## The Consultation

We want to talk to autistic people in different parts of the country.

You can give your views in an interview.

The interview can be at a time and place that suits you.
It will last between 30 minutes and 1 hour.

You can communicate your views in whatever way you choose.

If you are interested in taking part, please fill in the interest form.

You can change my mind at any time about taking part.
You can leave the interview at any point.

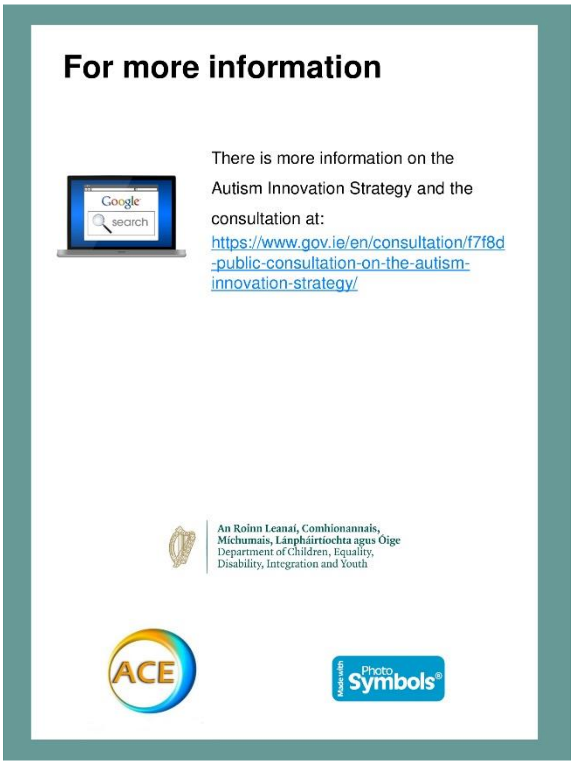
## The Consultation

Send the form to acecommunicationireland@gmail.com

If you would like more information, you can contact Teresa
085 141 0933
acecommunicationireland@gmail.com

There will be a report at the end of the consultation.
Your name will not be in the report.

We can send you a copy of the report if you want.



## For more information

There is more information on the Autism Innovation Strategy and the consultation at:
https://www.gov.ie/en/consultation/f7f8d-public-consultation-on-the-autism-innovation-strategy/

An Roinn Leanaí, Comhionannais, Míchumais, Lánpháirtíochta agus Óige
Department of Children, Equality, Disability, Integration and Youth

## Appendix 4 – Sample Talking Mat