



# Respect Our Rights!

What people with an intellectual disability  
have to say about how their rights under  
the UNCRPD are respected in Ireland

**November 2021**



**INCLUSION IRELAND**

[www.inclusionireland.ie](http://www.inclusionireland.ie)





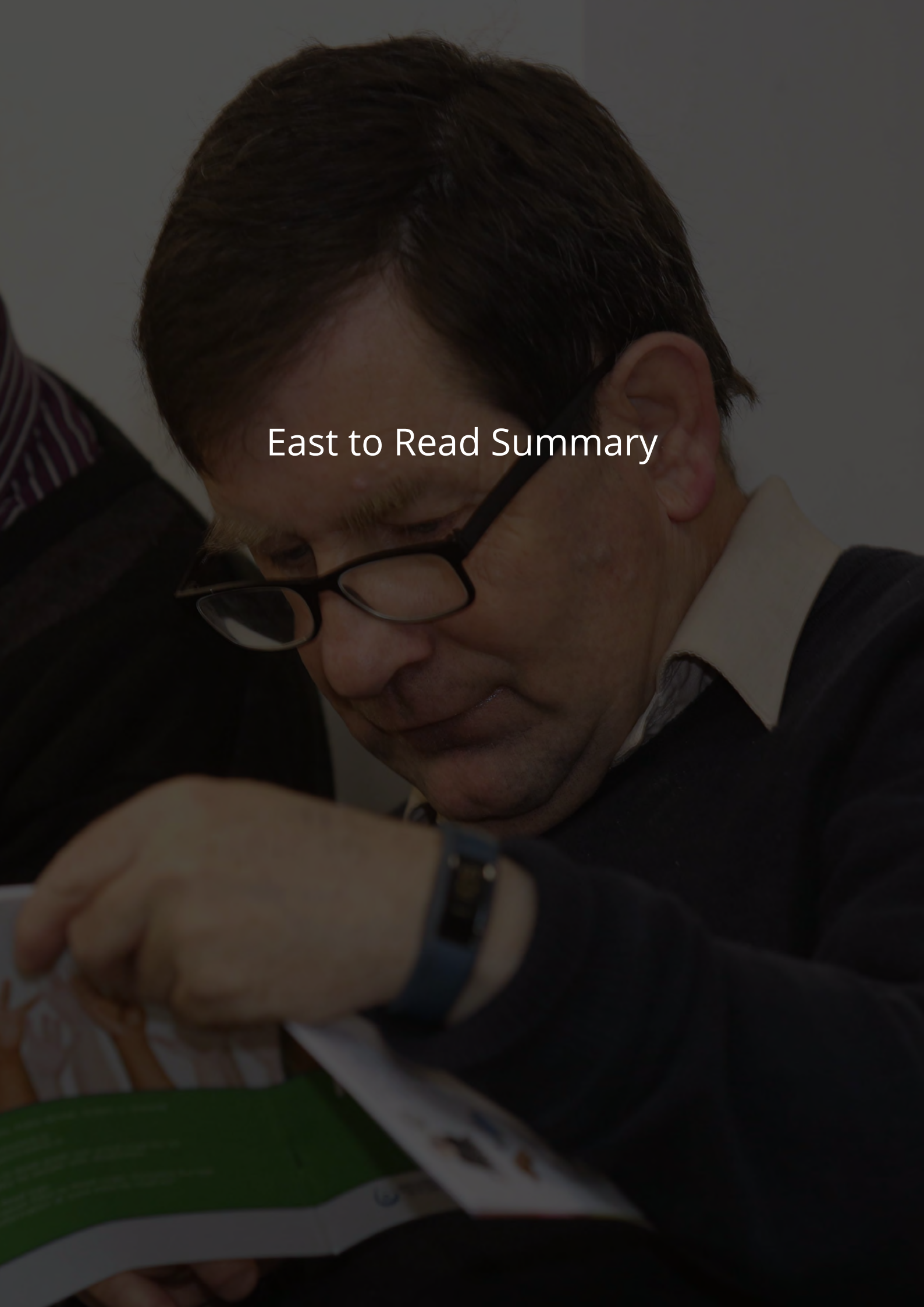
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A close-up photograph of a middle-aged man with dark hair and glasses, wearing a dark sweater over a light-colored collared shirt. He is looking down intently at a book he is holding. The book has a green cover. The image is dimly lit, with the text 'East to Read Summary' overlaid in white. A blue wristband is visible on his left wrist.

## East to Read Summary

# Easy to Read Summary



## What is the Shadow Report?

Ireland agreed to follow the UN Convention on the Rights of Persons with Disabilities in 2018.

This means that Ireland will be checked by an international committee called the Committee on the Rights of Persons with Disabilities. (The CRPD Committee for short)

The CRPD Committee will check if Ireland is doing a good job at respecting the rights of people with disabilities.



The Irish government will write a report to explain what they are doing to improve the lives of people with disabilities. It is called the State report.

People with disabilities will also write a report about their own experiences and what barriers they face in their lives. This is called the Shadow report.



## What did we do?

We organised 3 big Zoom consultations this year.

We talked to 200 people with an intellectual disability and 20 family members. We asked them about their rights and:

1. What are the barriers for people with disabilities in Ireland?
2. What should be changed to make things better for people with disabilities?

This report is a summary of the important things that people said during the consultations.



## How will this report be used?

This report will be included in the Shadow Report that we will send to the CRPD Committee. It will tell the committee what we think about how the rights of people with disabilities in Ireland are respected.



## Awareness of Disability



### What are the barriers?

People are looking down on us. Sometimes they use bad words about us. Their attitudes can be very wrong sometimes. We are not kids, we are adults.



People don't think we can do much. Sometimes it feels like they only give us the simple jobs that we don't like. We can't make our own decisions because they are made for us by other people.



### What should be improved?

We want people in the community and in schools to understand more about disability. There should be a whole month about disability not just one day.

People should respect us more. We should get the support we need to achieve our goals

Professionals working with us should get special training about disability. This is important so that they can work well with us.

## Accessibility



### What are the barriers?

People often think that access is just about being able to move around easily. But access to information is also very important to us.

Many documents are too hard to understand. For example, information about voting and vaccination.

There is not enough public transport in rural areas. Because of this we have to depend on our families. We can't be independent.



### What should be improved?

Information should be in easy to read or videos so that we can understand it.

We need more education for the public on how to make information easy to understand. We need to tell people why this is important.



We need more public transport in rural areas. Easy to read bus and train timetables can also help.

# Inclusive Education



## What are the barriers?

There is not enough support in schools for people with disabilities to be included.

Classes in schools are too big. There are not enough Special Needs Assistants and other supports.

There are not enough choices in special schools. Students in special schools cannot study all the subjects or take exams.

Students in special schools often have to travel long distances to get to school.



## What can be improved?

There should be more training about disabilities in schools so that all staff can understand what helps us to learn and take part.

There needs to be more places in local schools so that people don't have to travel outside of their community.

There should be better supports in schools so that people have the support they need. This can include more SNA's and therapy supports.

Guidance counsellors need to be in special schools to help students plan for the future.

Schools should also teach independent living skills to help people get ready for life after school.





## Day Services



### What are the barriers?

There is not enough one to one support in Day services.

There is not enough staff in centres to give good support. Some don't have enough training.

There are not enough choices in some Day services. Often everyone does the same thing again and again.

Day services were closed during Covid 19 so many people had no service.



### What can be improved?

People need more support for their personal interests.

Staff need more training and experience.

People need more choice and control over what they do and learn. They need opportunities to try new things.

## Employment and Work



### What are the barriers?

People don't think we can do much. They don't expect us to work. They think we can only do simple jobs.

They only think about our disability, not our ability.

School does not help us to get ready for work.

Some people look down on us in the workplace. Some of us have been bullied.

There are not many jobs that we can apply for. We don't get much support to get a job or to do a job well or to travel to a job. This makes it harder for us to get work.

If we work more than a certain number of hours, we can lose our disability allowance, our medical card and our travel pass.



### What should be improved?

People have to treat us more fairly and help us to get more confident and independent. Schools should help us to get ready for work.

Employers should get more information about support available to give jobs to people with disabilities. They should learn about our abilities.

We need better access to information and transport to work.

The Government should support us to get more jobs and keep them. For example, they could spend more money on job coaches to support us.

There should be more days for job shadowing and on-the job training.



## Independent Living



### What are the barriers?

It is hard to get a house and the support we need to live in the community.

Many of us are on a waiting list for many years and are still living with our parents.

It is hard to apply for housing. It is hard to get the support you need to live independently.

Many houses are not accessible. They also cost too much and are far away from our friends and family.

Many people don't get support to go out and mix with other people. They feel lonely.



### What should be improved?

The Government needs to build more houses that are accessible. It should be easy to travel from your house to do things in the community.

The county councils must do more to support us to live independently.

We should have the right to choose where we want to live and who we want to live with. We should be able to choose who supports us.

We should have more access to technology that makes it easier to live independently. This can really help people who need more support.

We should not feel alone when we move to our new home. We should get support to make friends and to do things in the community.



## Personal Choices and Relationships



### What are the barriers?

People often think that people with disabilities can't make their own choices.

Some people think that people with disabilities shouldn't have relationships.

People with disabilities do not have enough control over what they can do.

People with disabilities do not have enough privacy.

### What can be improved?

The public need more education on how to support people with disabilities to make their own choices and decisions.

People with an intellectual disability need

- More support with making choices and decisions
- More support and information about having relationships
- More opportunities to have control over what they do.
- More privacy inside and outside of services





## Speaking up for Yourself



### What are the barriers?

Our opinions are not always taken seriously by other people.

People see our disability not our ability to do things.

Sometimes we don't have the confidence to speak up.

We don't always know about our rights. It can be hard to get information that we understand.

There are not many people with intellectual disabilities who are leaders.



### What should be improved?

People should see that we have an equal right to take part in our community. We should be consulted about decisions that affect us.

There should be more funding for self-advocacy. We should be supported to become leaders.



We need better access to information so more people can take part.

We should be on the boards of companies that support us. We should be on committees that make decisions.



We should be in politics. We should be seen as leaders.

We would like to thank everyone who took part in the consultation.

We hope our report will help improve things for disabled people so that they have the same rights as everyone else in Ireland.



## About Inclusion Ireland

“The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights.”

## About Inclusion Ireland

**Established in 1961, Inclusion Ireland is a national, rights-based advocacy organisation that works to promote the rights of people with an intellectual disability.**

**The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights.**

**Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy and we use the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to guide our work.**

### Introduction

**In 2021 Inclusion Ireland worked with a Steering group of 6 people who have an intellectual disability, to plan and deliver a consultation process about how well the human rights of Irish people who have an intellectual disability are being respected.**

This consultation report reflects the views and lived experience expressed by more than 200 people with an intellectual disability and about 20 of their family members.

The main reason for the consultation was to inform a shadow report that Inclusion Ireland will send to the United Nations Committee on the Rights of Persons with Disabilities.

### What is the UNCRPD?

**The United Nations Convention on Rights of Persons with Disabilities (UNCRPD) says that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.**

The UNCRPD requires change, from viewing people with disabilities as receivers of charity, medical treatment, and social protection to viewing people with disabilities as

- people with rights, who are capable of claiming those rights,
- people who are capable of making decisions for their lives based on their free and informed consent and
- people who are capable of being active members of society.

The UNCRPD identifies 26 important rights that impact the lives of persons with disabilities. The Convention on the Rights of Persons with Disabilities was adopted in 2006 at the United Nations Headquarters in New York and came into force in 2008.

## What is a Shadow Report?

**Ireland signed the UNCRPD in 2007 and was the last country of the European Union to ratify it in March 2018.**

Ireland's implementation of the convention will now be monitored by the the Committee on the Rights of Persons with Disabilities (CRPD). Every 4 years, the Irish Government must send a report to the CRPD about how the rights of people with disabilities are being implemented in Ireland. This is called the State's Report.

An important requirement of this monitoring process is that people with an intellectual disability should be actively involved in the monitoring process.

Non-government Organisations and Disabled Persons Organisations (DPOs) such as Inclusion Ireland are allowed and encouraged to present alternative reports to the CRPD. In these reports, people with disabilities present their own experience of how the state is respecting their rights in Ireland and the barriers that they face.

These alternative reports are called shadow reports. The UN Committee reviews these shadow reports as well as the report presented by the Irish Government.

The Committee on the Rights of Persons with Disabilities (CRPD Committee) will examine the Irish reports and answer back to the Irish Government with a **List of Issues** that asks questions and asks for more information.

Ireland must then follow up with a **Reply to the List of Issues**, with answers to the Committee's questions and the extra information the UN committee asked for.

The UN Committee then issues Concluding Observations, in which they make suggestions and general recommendations about the implementation of the UNCRPD in Ireland.

## How did we organise the consultations?

In January and February 2021, after an online advertisement and interview process, Inclusion Ireland recruited six steering group members, all of whom have an intellectual disability. The group was carefully selected to ensure that there was a good mix of age, gender and geographical location.

After some initial training with two Inclusion Ireland staff members, the steering group agreed 7 key themes, based on the UNCRPD articles, that were directly relevant to the life experience of people with an intellectual disability. Through a series of Zoom interviews based on these themes, seven videos were made that highlighted key issues experienced by people with an intellectual disability in Ireland. Below is a set of links to the videos made under each theme:

**Accessibility and Awareness Raising**

**Participation in public and political life**

**Independent Living**

**Personal Choices and Relationships**

**Inclusive Education**

**Day Services**

**Employment**



[CLICK FOR LINKS](#)



The steering group then worked with Inclusion Ireland staff to plan and deliver three online consultation events. The relevant videos were circulated to self-advocacy groups, allowing time for each group to discuss topics and prepare in advance of the Zoom consultations.

13 different advocacy groups engaged with the process. Most advocacy groups sent two people to represent the views of their group at each of the three consultation events. Video packs were also sent to individuals who registered separately for the event.

The 3 consultation events were held in May, June and July. At each consultation event participants considered 2 or 3 of the themes identified above, and they discussed “What is hard for us?” and “How can we improve things?”

The consultations were led by people with an intellectual disability. A steering group member acted as a Master of Ceremonies in the main room for each of these events and facilitated feedback from the breakout rooms. Different steering group members gave presentations in the main room on the CRPD and Next Steps. Some of the advocacy groups also prepared short videos that were shown in the main room.

There were seven breakout rooms at each event, 6 for people with an intellectual disability and 1 for family members. Each of the breakout rooms was hosted by a steering group member who facilitated discussions with the support of an Inclusion Ireland staff member. Each breakout room was also supported by a note taker to record the views expressed.

Although the Covid19 context was challenging, working online created an opportunity for people from many different parts of Ireland to connect remotely with their peers, both in the Steering group and in the consultations.

*“The relevant videos were circulated to self-advocacy groups, allowing time for each group to discuss topics and prepare in advance of the Zoom consultations.”*

A group of people, including men and women, are participating in a protest or demonstration. They are holding up white signs with black text. The signs read: "LET US MAKE OUR OWN DECISIONS", "NOT A LUNATIC", "COMMENCE THE ACT", and "WE WANT SUPPORT". The background is slightly blurred, showing trees and a city street.

1

## Awareness Raising

“Raise awareness throughout society of the abilities and potential of persons with disabilities.”

**Article 8 UNCRPD**

# 1

## Awareness Raising

### Article 8: Awareness Raising



[CLICK FOR LINK](#)

#### Context in Ireland

**According to a National Disability Authority (NDA) Survey in 2017, 28% of people believe that children with intellectual disabilities and autistic children should not be educated in the same school as non-disabled children.<sup>1</sup>**

The NDA survey also showed that adults who have an intellectual or emotional disability are more likely to receive negative treatment in the workplace compared with people with physical disabilities. Overall, only 18% of respondents believed that people with disabilities receive equal opportunities in terms of employment

The National Disability Inclusion Strategy 2017-2021 (NDIS) sets clear objectives to

- Provide disability awareness training for all staff in public services
- Raise awareness amongst employers through the Employer Disability Information service.
- Foster awareness in voluntary, sporting and cultural organisations and “disability-proof ” funding programmes for these organisations.<sup>2</sup>

In spite of these objectives, the findings of this consultation show that public attitudes towards disability remain a real obstacle to inclusion in all aspects of life for people with intellectual disabilities in Ireland.



<sup>1</sup> National Disability Authority, National Survey of Public Attitudes to Disability in Ireland, 2017

<sup>2</sup> National Disability Inclusion Strategy 2017 – 2021, 4-employment

## What is hard for us about people's attitudes?

### Negative Stereotypes

Participants felt that there is often a lack of respect and understanding within Irish society towards disabled people. The attitudes of people can be disrespectful, and the words used by others about people with an intellectual disability can be demeaning and hurtful. The segregation between special and mainstream schools in the education system, reinforces this culture of difference and exclusion by denying opportunities for interaction, that could develop awareness, tolerance and understanding at a formative age.

*"People are using not socially acceptable language, the communication on people with disabilities is wrong."*

*"People are looking down on us."*

*"We can be stopped by other people from going to the shop and other buildings because we are not accompanied by another adult."*

### Low Expectations

A consequence of this negative stereotyping is that people are seen as less able and are often not given a voice or consulted on things that matter to them. These negative stereotypes also impact on the employment prospects of disabled people. Employers and supporters may have very low expectations for them and may not believe that people with intellectual disabilities can do valuable work.

*"Our decisions are made for us and because of this, we are not treated fairly."*

*"It feels like there is an asterisk around our opinion."*

*"We are giving the worst jobs to individuals with disability."*





## How can we improve things?

### General Awareness-Raising

Participants felt that the general public, employers and public service staff should be re-educated on disability through training and media campaigns that are led and strongly informed by people with disabilities themselves.

*"More awareness should be created in the society about people living with disability."*

*"There needs to be education for people on disability and attitude beginning in school."*

*"There should be a disability month like Pride month with ability advertising campaigns."*

### Specific Training

Staff working in public offices should be given training on how to communicate in an easy way and treat everyone with respect. Families, professionals working with disabled people and the wider community also need to be educated on how to support people with an intellectual disability to make decisions and choices, as opposed to making decisions for them. Finally, more people with disabilities should be involved in politics and public leadership roles in order to change perceptions about their capacity.

*"Staff in specific buildings (for instance shops and public offices) should be given proper training in how to communicate with individuals with disabilities so that they understand not to take our independence away from us and to treat us like everyone else/ fairly"*

*"People should respect us more and we should get the support we need to achieve our goals."*

*"Less support should be provided to those who do not need the extreme amount of support that is usually given so that our independence is not taken away from us."*

*"Let people try before denying them the right."*

## 2

### Accessibility

“Ensure easy access to information, communications and transport.”

Article 9 UNCRPD

# 2

## Accessibility

Article 9 - Accessibility

Article 20 - Personal Mobility

Article 21 - Freedom of expression and opinion and access to information



[CLICK FOR LINKS](#)

### Context in Ireland

#### *Accessible Information*

The NDIS 2017-2021 states that public sector information has to be available in formats that are easy to understand. It also contains specific obligations for Court and Garda (police) services to be accessible.

The Public Sector Duty places an obligation on public bodies to promote accessibility and inclusion. One way of enhancing the accessibility of information is to invest in assistive technology and provide training and support in Information and Communications Technology (ICT).

#### **Accessible Transport**

The Mobility Allowance and Motorised Transport Grant, was discontinued in 2013. These two schemes were originally established to support people with disabilities to access transport. Private transport is a significant extra cost for households with a disability and this decision has placed people at an even greater risk of social exclusion. Plans for a new Transport Support Scheme were announced shortly after the schemes were discontinued, but have not been put in place to date.

In addition, the National Disability Inclusion Strategy 2017-2021 sets out a range of commitments with the aim of ensuring that “persons with disabilities can get to and from their chosen destination independently (without driving a car) in transport that is accessible to them”. The Strategy aims to improve the accessibility and availability of inter-city buses, train and bus stations, and transport information.

In spite of these goals, the availability and accessibility of transport, especially in rural areas, is a significant issue for people with an intellectual disability. The absence of accessible services leads to increased isolation and a sense of being cut off from services and community supports. Where public transport is poor, unavailable or inaccessible, people are reliant on private services.



## What is hard for us about accessibility?

### Lack of access to information

Participants said that state initiatives to tackle accessibility focused more on physical than intellectual disabilities. Many administrative documents and processes are not accessible to people with intellectual disabilities. Accessible communication and information are not often available at meetings where important issues are being discussed and decisions that affect the lives of people with an intellectual disability are being made. When people are included in meetings, they feel that it can be tokenistic and that they are not given a real chance to participate.

*“Process and paperwork to get jobs or houses is hard.”*

*“Instructions and documentation are not easy read. Vaccination, voting are examples of difficult info.”*

*“Lot of written direction like in the cinema or on toilet doors are not easy to read.”*

*“Many administrative documents and processes are not accessible to people with intellectual disabilities.”*

### Lack of access to transport

Access to transport is an issue, especially in rural areas, and it makes people more dependent on families to get from one place to another.

*“It’s difficult to get from place to place without relying on family.”*

*“Important services are too complex like employment, education and banking forms.”*





## How can we improve things?

### Awareness raising on accessibility

Participants highlighted the need to educate the general population about accessibility, why it is important and that it is about more than just physical accessibility.

*"The public should be educated about what access is and how important it is"*

*"We need more awareness of accessible information like easy-to-read documents"*

*"Focus is always more about physical access only"*

### Access to Information/Communication

There should be better access to information through a simplification of instructions, paperwork, and administrative processes. Some initiatives such as rolling out JAM cards or having communication boards and easy to read materials in all public buildings should be developed and supported by the government.

*"Better initiatives to connect us with society. Easy to read language and "to the point" English that could be understood."*

*"More easy to read documents and words, there needs to be more signs, pictures."*

*"There should be more easy to read social and political information."*

*"Access information is hard like filling out job and housing forms – we might need easy read information or a person to help us with the forms."*

### Training

Training was raised by many participants as a key solution to raise awareness amongst staff in the public and private sector about how to make information and communication more accessible for people with an intellectual disability.

*"There should be seminars about accessible workplace presented by people with disabilities"*

*"With a speech therapist, we trained staff members in McDonald how to communicate with people with intellectual disabilities".*

### Transport

Finally, more should be done to make transport accessible to all, including in rural areas. For example there could be Easy to read and/or audible bus/train timetables.

*"We need more transport in rural areas so people with disabilities can access work, college, socialising and other activities in the community and we need more accessible rural transport to access community services."*



# 3

## Inclusive Education

“Ensure an inclusive education system  
at all levels and lifelong learning.”

**Article 24 UNCPRD**

# 3

## Inclusive Education

### Article 24 - Education



[CLICK FOR LINK](#)

#### Context in Ireland

**In Ireland, the legislation specifically focusing on addressing the needs of children with disabilities is the Education for Persons with Special Educational Needs (EPSEN) Act 2004. While the Act puts inclusive education on a statutory footing, it allows for an exception to this principle.<sup>3</sup> Inclusive education is the default position except for 'where it is not in the interest of a child'.**

The EPSEN Act also provides for a statutory assessment of supports and an individual education plan. These provisions of the Act have never been fully commenced.

The UNCRPD was ratified by Ireland in 2018, but it sits uneasily with the EPSEN Act, because the Convention does not allow for exceptions to inclusive education. It has been made clear in both the CRPD general comment 4, and in the assessment of other countries by the CRPD Committee, that special schools and special classes do not fall within the definition of inclusive education.

The budget on special education has been increased by a significant amount in recent years with increased provision of resource teaching and SNA support. However, a significant amount of the increase in the special education budget has been spent on segregated education provision with autism classes (in particular) increasing in number year on year. Segregated special classes have increased from about 700 to almost 1800 between 2012 and 2019. Figure 1 below shows the yearly increase in the provision of segregated special classes.

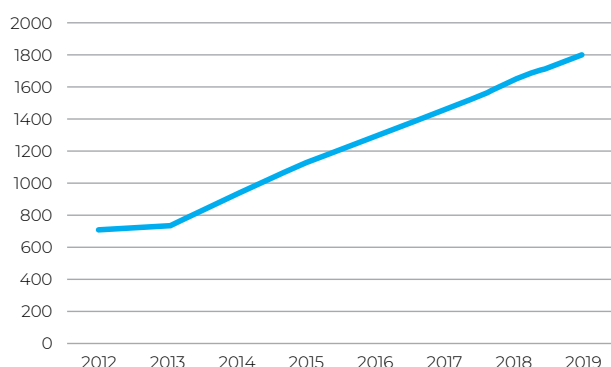


Figure 1: the growth in special class provision in Ireland

There are currently over 16,000 students educated in either a special class or a special school. There are 1,620 special classes in the country and 8,400 students educated in special schools throughout Ireland<sup>4</sup>. A parallel system of education provision exists in Ireland at present, with around 2% of pupils being educated in segregated classes and schools.

The Education (Admission to Schools) Act 2018 introduced reforms, which made it easier for a child to access their local school. Section 8 – Special Classes, provides the Minister with the power to compel a school to make additional provision in respect of children with special educational needs i.e. open a special class or classes, where the National Council for Special Education (NCSE) has identified a need for such provision within an area. However, the Act has not been commenced at this stage and schools are still refusing children on an arbitrary basis.

<sup>3</sup> More information about the EPSEN act can be found in Inclusion Ireland 2020 submission to NCSE, p6.

<sup>4</sup> NCSE (2019). Policy Advice on Special Schools and Classes. An Inclusive Education for An Inclusive Society?

## What is hard for us about education?

### Lack of Awareness

Self-advocates pointed out the lack of awareness in schools, that not everyone is treated the same, and that people with disabilities can be stigmatised. Teachers do not receive proper training and often lack experience when it comes to teaching pupils with disabilities.

*"Teachers do not receive proper training. They lack experience"*

*"Not everyone is treated the same."*

### Lack of Support

People lack support at school: the teachers are not supportive enough and there are not enough Special Needs Assistants (SNAs). The classes, especially in mainstream schools are too big to be able to provide enough support to pupils. The discrepancies from one county to another in the level of the provision of support were also raised.

*"I was not diagnosed early enough"*

*"I found it difficult with reading and writing."*

*"Lack of staff that can give more 1 to 1 help."*

*"Lack of info on courses, if information is available, it's often not in an accessible format."*

*"Teachers not being supportive enough."*

*"Rights to education shouldn't stop at 18 just because we have a disability."*

*"Lack of consistency around the availability of supports in different geographic areas."*

*"Lack of resources in mainstream schools."*

### Exclusion

Finally, the segregation between the mainstream and special schools was highlighted. Children in special schools are more limited in their choice of subjects, cannot take the same exams, and often have to travel long distances outside their communities to go to their schools. Students in special schools do not have access to career guidance and they are often expected to go straight into day services once they finish school.

*"Specials schools aren't appropriate cause we don't get to mix with other people."*

*"Children have to leave their community for education."*

*"Separate school to siblings and long journey to special school."*

*"Resource classes - felt excluded/left out. Everyone should learn together."*

*"I was not able to mix with everyone. Social life was difficult."*

*"Parents shouldn't have to fight for their child's education, it should be a given."*

### Limited Opportunities

*"I didn't get to experience secondary school."*

*"I did not have the opportunity to do Irish in primary school."*

*"I was not able to do the leaving certificate or junior certificate."*

*"I was unable to do the exam because there wasn't much access for wheelchairs."*

*"It's too late for my son he is an adult now."*

## How can we improve things in Education?

### More Awareness-Raising

Participants highlighted the importance of training school staff (administration, board, teachers, parents) on disability and helping them to understand the issues faced by people with disabilities.

*"Kids with disabilities should be treated just like everyone else."*

*"Being included, being belonging, that's the way it should be in any school or in any place."*

*"We would like that everybody would have the opportunity to be included and learn together."*

### Access to Schools

More places in schools need to be created so pupils will not have to travel a long distance to go to their schools.

*"To provide special schools in the local area - rather than travelling long periods to get to school."*

### Better Support

Within the schools, while the class size should be reduced, there should be an increase of SNAs to provide more 1:1 support. More specific services such as speech and language therapy, mental health units, guidance counsellors should be made available in mainstream schools. Specific support should be provided in the transition from primary to secondary school and to explore post-school options.

*"There should be more access to support, more choice of subjects and get better prepared for work."*

*"Fear of my child not having somewhere to go for secondary school."*

*"Education needs to continue after 18".*

### Empowerment

Finally, the emphasis should be put on empowering students to develop not only academic skills, but also social and independent living skills.

*"Let people with disabilities take the leaving certificate and do the same subjects as others."*

*"I think teachers should make a difference like let their students make their own decisions instead of the teachers making the decisions for them. Let the teachers ask them what they think they should do with them."*

*"It is important to learn more life skills, being more active, and going on trips."*

*"There should be more information on courses and given in a more accessible way."*

*"The opportunity when you finish school to go to further education (secondary and college)."*



# 4

## Day Services

“Enable maximum independence and full inclusion and participation in all aspects of life.”

**Article 26 UNCRPD**

# 4

## Day Services

Article 19 - Living independently and being included in the community

Article 26 - Habilitation and Rehabilitation



### Context in Ireland

[CLICK FOR LINK](#)

**HSE-funded day programmes for people with intellectual disabilities, autism, or complex physical disabilities include a range of centre-based and community-based activities. There are day services of different kinds, and some sheltered work.**

Most of these are long-term programmes with typically lifelong participation, although the mix of activities and supports can change over the person's lifetime.

Formalised disability day programmes for adults are delivered by over 90 service provider organisations at over 1,000 locations. Adult day programmes are the second-largest area of State expenditure on disability services, accounting for about 21% of the disability services budget.

The HSE database shows that around 16,400 people were in a formalised disability day programme at the end of February 2020 and in addition around 2,250 people with disabilities participated in Rehabilitative Training.<sup>6</sup>

A transition is under way from traditional centre-based day services to the New Directions model of person-centred supports, based on the individual's needs and wishes. The focus is on supporting people to participate in the mainstream activities and in the life of their community.

The main driver of change for this transition by providers, is a self-assessment process against a set of standards for New Directions that has been developed by the HSE.<sup>7</sup>

In a review of this self-assessment process carried out in 2018, one of the main challenges highlighted by service providers was the difficulty of engaging the people supported by the service, in the evaluation of the service.<sup>8</sup> This finding indicates that the people supported within day services do not commonly experience the support relationship as an empowering one.

The other potential driver of change in this area is Personalised Budgets, a process which would allow a person who is supported by a service, to have much greater discretion and control over the supports that they receive. A government task force reported on this in 2018<sup>9</sup> and a pilot process to implement the recommendations of the taskforce is currently under way.<sup>10</sup> Early feedback suggests that the process of identifying and "unbundling" personal allocations in order to enable this pilot project, is proving challenging.

<sup>5</sup> [Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032](#)

<sup>6</sup> Disability Capacity Review to 2032 – Department of Health 2020 – p. 85

<sup>7</sup> [New Directions - Interim Standards for New Directions, Services and Supports for Adults with Disabilities](#)

<sup>8</sup> [Interim Standards New Directions Review of Evaluation, Action and Service - Improvement \(EASI\) Process Report](#)

<sup>9</sup> [Task Force on Personalised Budgets](#)

<sup>10</sup> [Personalised Budgets for People with a Disability](#)



[CLICK FOR LINKS](#)

## What is hard for us about Day Services?

### Lack of Support/Personalised support

Some participants had positive experiences in their day services. Others highlighted a lack of personalised support in the day services due to the lack of staff or short days in the centre.

*"We are too many people and not enough support."*

*"They don't focus enough on individual interests."*

*"Some people don't have a person-centred plan (PCP)."*

### Lack of Staff and Training

The staff do not always have the experience and the training required to effectively support the people who attend the day service.

*"The staff is not experienced enough, they don't have enough training on teaching tasks."*

*"They cut staff to go to other day services – we need more staff."*

*"There is not enough staff- for supporting us to do things independently (shops etc.)"*

### Lack of Control/Limited opportunities

Many pointed out the lack of control they had in terms of choosing their activities or getting the support they wanted. Some people felt that they were not listened to enough or treated well. Finally, they found that they not only had limited social opportunities to interact with other people in their communities, but they also had a lack of employment opportunities.

*"I was not given options on choice of services"*

*"The staff make too many decisions –we are told what to do"*

*"Sometimes not listened to enough"*

*"Don't have social opportunities"*

*"Day Services are not for some people -some would prefer open employment"*

*"I don't get support to get a job"*

### Lack of Stimulation

Some participants also felt that there was a lack of stimulation and that the daily activities were repetitive.

*"I am with the same people all the time. I'd like to meet people from other services."*

*"It's repetitive – we do the same work all the time."*

*"We don't learn about living skills."*

### Closure/Restriction

Participants also highlighted how the Coronavirus pandemic worsened the situations in day services in terms of the support that they received and their access to activities.

*"Activities are cut- less choice because of COVID."*

## How can we improve things in Day Services?

### More Choice and Opportunities

Participants highlighted the need for a wider range of choices and opportunities in their day services. This includes a wider range of activities inside and outside the service, the possibility to meet people from different services, more work-oriented tasks, and a better connection with the community.

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*"There should be more activities to meet the participants' interest e.g. animals etc."*

---

*"It would be nice to have the opportunity to get involved with community with volunteer work."*

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*"I want more social opportunities."*

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*"Day services need to be more inclusive in the community."*

### More Control

There should be more flexibility from the services to adapt to the individuals' will and preferences. Services should give more control to service users in the way the support is being provided.

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*"They should hear and listen to people's opinions- put person at centre and be there to listen when they're feeling down."*

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*"It is important for service users to be respected, listened to and having staff to help them reach their goals."*

---

*"We need lots of choice to meet new people and to do new things in line with your interests that might lead to employment."*

---

*"We also want the term "service users" to be changed."*

### Better Support

This should be made possible through an increase of staff, more 1 to 1 support and longer hours. This support should empower people by developing their independent living skills, social skills and helping them to access programmes and courses. Finally, people said that everyone should be supported in the services, including those with higher support needs.

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*"More staff and every service should have meetings so that people can tell the managers about their problems."*

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*"More staff to support people to do things outside of day services."*

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*"All day services should have frequent meetings- about what's going on – changes."*

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*"I need to have support through job with a job coach."*

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*"Every person should have access to a coordinator to support person to meet goals in Person Centred Plan and access the activities, learning opportunities and experiences we want."*

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*"We love social activities, support to develop independent living skills and support for jobs."*

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*"Don't forget people with higher needs of support, they need to be included and not forgotten about."*



A woman with dark hair tied back, wearing a dark button-down shirt, is smiling and looking towards the camera. She is standing behind a stainless steel counter in what appears to be a kitchen or food service area. In the background, there are shelves with various items, including a box of tissues and some containers. The lighting is warm and slightly dim, creating a professional yet approachable atmosphere.

# 5

## Employment

“Ensure the right to work, on an equal basis with others.”

**Article 27 UNCPRD**



# 5

## Employment

### Article 27 - Work and Employment



[CLICK FOR LINK](#)

#### Context in Ireland

**The Irish government has a current commitment that 3% of employees in the public service should be disabled people. It has promised to raise this to 6% by 2024. The Comprehensive Employment Strategy 2015-2024 for people with disabilities in Ireland has 6 priority areas: building skills, capacity and independence; providing bridges and supports into work; making work pay; promoting job retention and re-entry into work; providing co-ordinated and seamless support; engaging employers.**

According to a recent report from the National Disability Authority, at the end of 2019, public bodies reported that 3.1% of employees employed in the public sector are people with disabilities. This is a decrease from 3.3% in 2018 and takes place in the context of an overall increase (+2.8%) of employees in the public sector. However, a slight improvement has been noticed in the number of public bodies who have reached the target of 3% of employees with disabilities.<sup>11</sup>

According to Ireland's Census 2016, 36% of people with disabilities of working age (age 20-64 years) are in employment, compared to 73% of the general population. This rate is one of the lowest in the European Union where on average, 50.6% of people with disabilities are in employment. Employment rates in Ireland are even lower among those with intellectual disabilities: only 17% of those with an intellectual disability are in employment.<sup>12</sup>

According to Ireland's Health Research Board, statistics published in 2017 reveal that less than 1% of people registered with the National Intellectual Disability database are in open employment. If those in supported employment or an enclave within open employment are included, the figure rises to 4%.

As outlined above, adults who have an intellectual disability are more likely to receive negative treatment in the workplace compared to people with physical disabilities. Overall, only 18% of respondents believed that people with disabilities receive equal opportunities in terms of employment

In 2017 A Make Work Pay report identified the following key changes that are needed in employment policy and supports in order to enhance the employment prospects of disabled people.

- i. Build skills, capacity and independence
- ii. Provide bridges and supports into work
- iii. Make work pay
- iv. Promote job retention and re-entry to work
- v. Provide coordinated and seamless support
- vi. Engage employers

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<sup>11</sup> 2019 Report on Compliance with Part 5 of the Disability Act on the Employment of People with Disabilities in the Public Sector, released in 2021

<sup>12</sup> National Disability Authority, National Survey of Public Attitudes to Disability in Ireland, 2017

## What is hard for us about employment?

### Bad Attitudes

Many participants reported negative attitudes that they encountered in the workplace such as being treated unfairly, being looked down on, being bullied, and being underestimated in their ability to perform certain tasks.

The low level of employment also creates a vicious circle where people with an intellectual disability, and the wider community, do not see and experience the paid employment of people with an intellectual disability as a cultural norm.

*"In the workshop, when you went to the toilet or anything, the supervisor used to time you... they gave us 2 euros a week for working in the shop for 10 hours."*

*"They only think of disability not ability."*

*"If you don't have any education, the employer will be like, oh no this person doesn't have the education needed for the job."*

### Lack of Accessibility

Several workplace accessibility issues were highlighted including:

- Access to information about job announcements and recruitment processes
- Accessible communication and information once one starts to work on-site.
- Access to transport

*"Transport to the job is hard."*

*"I did not get the information for what to do in my work."*

### Lack of Support

Participants described how a lack of support from schools can negatively impact employment opportunities in the future. Moreover, once employed, the level of support provided varies greatly from one place to another.

*"They don't focus enough in schools on individual's strengths that can lead to employment."*

*"Not enough training for employers to employ people with disabilities."*

*"Some jobs more supportive than others."*

### Lack of employment opportunities/ poverty

Many pointed out the lack of employment opportunities, and the limited career advancement available to them. The state targets on public sector employment do not benefit enough people with intellectual disabilities and the few positions that they are currently accessing are usually limited to low skills jobs without hope of career advancement. The Covid 19 pandemic has also significantly impacted catering and other service industries where employment was previously open to people with intellectual disabilities.

*"The government says that we have to employ people with a disability but the people we employ are people with physical disabilities."*

*"Most of these people with disabilities are only in voluntary work. And they are not getting paid for it, they only get their Disability Allowance. They can't go on holidays, they can't have social lives. They can't do anything!"*

*"You used to see people with disabilities in cafes. But you always see them wiping down the tables or cleaning the ladies and gents. But you would never see them at responsible jobs like taking the money."*

## Benefit Trap

Finally, the risk of losing the disability allowance and the attached benefits (medical card, travel card) for people working more than a certain amount of hours was pointed out as a great obstacle.

*"The main obstacle would be the Disability Allowance, if you have a Disability Allowance, you're not allowed to earn over a certain amount of money cause if you do they'll take it away and they'll take the bus pass and medical card and all."*

*"We got on to Social Welfare. We had a talk with the person in charge. He told me I'm only allowed 20 hours a week. And if you go over these 20 hours he told me, all these benefits will be taken off you."*



## How can we improve things in Employment?

### More Awareness

Raising the awareness of employers and non-disabled staff was seen to be crucial. This could be achieved through training, more days for job shadowing, and more visibility of staff with intellectual disabilities in open employment to show that it can be done.

*"There should be more days for job shadowing."*

*"Treat us with respect in the workplace to help with our independence and confidence."*

*"Staff with intellectual disability needs to become more visible and employment seen as the norm. It should be part of corporate responsibility of companies and specific target in public service."*

*"They have a disability committee in A&L. I am a part of this disability committee. We talk about disability in the office, promote it. They try to look at the way the office is set out? is it accessible or not?"*

### Better Accessibility & Information

There should be better access to open employment:

- Easy to read application forms
- Address perceived barriers about health and safety
- Support employers to provide paid work, not just volunteering

Participants also highlighted the need to improve access to information for employers so that they know more about the existing schemes and the support they can get to hire workers with disabilities.

*"They need to make it easier for us to apply for jobs."*

*"We need to support employers to provide paid work, not just volunteers."*

*"Health and safety need to be improved in workplace to allow people to have paid jobs."*

*"It's important to know the physical risks of the job before starting"*



## Better Support

An increase in job coaches/ buddies should be made available on-site, especially when people are starting a new job. Specific supports should be made available when someone is starting to work such as: transport, work with colleagues, safety rules etc.

*"It's important to get more travelling experience and help to get to work."*

*"Having support in work at the start. More 1-1 support to get a job and when you are starting your job."*

*"There should a bit of training and there should be a person that is tied to yourself."*

*"In NUI, I was lucky that I had my buddy. You have someone you can go to when you start. Your buddy would meet with you."*

*"More support workers and more support to become more confident".*

*"We need to include people with higher needs and support them."*

*"It's important to find a balance between assistance and independence."*

*"Get more help with how to talk to customers."*

## More Job Opportunities and Flexibility

More job/training opportunities are needed to multiply people's experiences on the labour market in areas such as retail, cafés and the public service. A mandatory percentage could be implemented to hire specifically people with intellectual disabilities. Finally, there should be more flexibility around the possibility to work while keeping the Disability Allowance and the attached benefits.

*"Schools should provide more subjects for people with disabilities that will help them to get into employment or setting up their own business."*

*"The important thing is to take them on and pay them the proper money."*

*"They should include more people with disabilities into civil service roles."*

*"They should put a percent of employees with intellectual disabilities to be hired."*

*"If people with disabilities want the job, they can keep the Disability Allowance and they can have more hours and earn more money."*



A photograph of two women sitting and laughing heartily. The woman in the foreground is wearing a brown sweater and a patterned scarf, while the woman in the background is wearing a leopard print top. The image is dimmed to serve as a background for text.

## 6

### Independent Living and Housing

“Ensure the right to full inclusion and participation in the community.”

**Article 19 UNCRPD**

# 6

## Independent Living and Housing

Article 19 - Living independently and being included in the community

Article 28 - Adequate standard of living and social protection



[CLICK FOR LINKS](#)

### Context in Ireland

**The need to move away from institutionalised living for people with disabilities has been a feature of Irish policy for decades. Multiple reports have made recommendations on the need to move from institutionalised settings to community living arrangements with access to community-based services.<sup>13</sup>**

In June 2011, the HSE published a strategy designed to implement deinstitutionalisation in Ireland. 'Time to Move on from Congregated Settings – A Strategy for Community Inclusion' focused specifically on 4,000 people in 72 centres which it called 'congregated settings' defined as ten or more people sharing a single living unit or where the living arrangements are campus-based. Publication of the strategy was considered a milestone and established a national policy for a new approach to community living for persons with disabilities.

'Time to Move On from Congregated Settings' painted a grim picture of isolation, segregation, lack of basic privacy and lack of dignity. The report was damning in its depiction of institutional life which resulted in "lives lived without dignity".

Despite the limited ambition of this strategy in focusing on large 'congregated settings', it is now clear that the policy has failed. The strategy was clear in recommending that all congregated settings would be closed within 7 years (by 2018). At present, 2841 people are still living in congregated settings.<sup>14</sup> The majority of these people have an intellectual disability.

A recent report "Wasted lives" released by the office of the Ombudsman highlighted the situation of 1300 disabled people under the age of 65 who are living in nursing homes.<sup>15</sup>

Many others are living in their family homes, waiting indefinitely on a housing list to move out and live independently. In a 2018 survey by the National Federation of Voluntary Bodies, in a sample of 18 of the 59 member organisations, there was 473 individuals living at home with a parent who was between the ages of 70 and 79 years. In these same 18 services there were 183 people supported by a carer who was over 80 years of age. Many more parents between the ages of 60-69 were providing the primary care role in the home. The survey estimated that more than 1250 disabled people are living at home with a primary carer over the age of 70 with 400 of these carers over the age of 80.<sup>17</sup>

Others do not have any housing options. In this regards, disabled people make up 13.5% of the population but make up 27% of the homeless population in Ireland.<sup>18</sup> Similarly, the risk of poverty rate among people out of work due to disability is 37.5% as opposed to 12.8% in the general population.<sup>19</sup> This is mainly due to low employment rates for disabled people.

<sup>13</sup> For example, the Report of the Review Group on Mental Handicap Services (1990); Towards an Independent Future, the Report of the Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities (1996); report of the Commission on the Status of People with Disabilities (1996)

<sup>14</sup> HIQA Annual Report 2020.

<sup>15</sup> Office of the Ombudsman, Wasted Lives-Time for a better future for younger people in nursing homes, 2021.

<sup>16</sup> [Funding Crisis in Disability Services](#)  [CLICK FOR LINK](#)

<sup>17</sup> National Federation of Voluntary Service Providers, Members survey, 2020

<sup>18</sup> Central Statistics Office, Census 2016.

<sup>19</sup> Central Statistics Office, SILC, 2019.



*“The situation for disabled people is exacerbated by high purchase and rentals costs, high levels of poverty, discrimination, and poor levels of employment.”*

Inclusion Ireland have long advocated on the housing crisis that exists for disabled people in Ireland. This is not a simple problem because the wide variety of housing situations and needs experienced by disabled people will require multiple housing solutions. The situation for disabled people is exacerbated by high purchase and rentals costs, high levels of poverty, discrimination, and poor levels of employment.

A recent report assessed the current level of unmet needs and projects the level of needs expected for the next ten years in Ireland. It highlights the shortfall of between 800 and 2300 residential places meaning the HSE will need to provide 90 additional places each year up to 2032 to meet demand.<sup>20</sup>

It also estimates the unmet needs for a personal assistance service (PAS) that has not been accurately measured. Significant investment is required of €4m in 2022, rising to €15m in 2032. It is estimated that an investment of €30m per year is needed to address the needs of people not in receipt of any PAS service at present.<sup>21</sup> About 2,500 people get a PA service averaging around 12 hours a week, often people who require a personal assistance service to live independently are not receiving a service which meets their need to have choice and control over their lives. Information in the disability capacity review confirms that from 2008 to 2018 there was no increase in the number of hours under the personal assistance service (PAS).

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<sup>20</sup> Department of Health, Disability Capacity Review to 2032, 2021.

<sup>21</sup> Ibid



## What is not right about housing?

### Lack of Houses/Infrastructure

The lived experience of the lack of resources for independent living documented above could be clearly heard from the participants. They pointed out the lack of available, accessible, and affordable houses. This situation leads many of them to be on endless waiting lists and to rely on their families. Some of them had experienced proposed housing solutions that did not fit their needs due to issues such as remoteness from family and other supports, rural isolation, and lack of access to transport.

*"I'm 27 and I'm still living at home with my nana and it's not getting any better for me. I have been waiting over 2 years for independent living. Waiting, that's it, crazy! I'm sorry but it is! It's absolutely crazy! There are so many people on that waiting list."*

*"We can't get a house and it makes us more dependent on our families. I'd like my family just to be my family, not my carers."*

*"I can't access transport where I am so I am relying on other people to drive me."*

*"The location of houses is not great. It can be really far from our families or services."*

### Lack of Support

The lack of support to apply for supported living housing was raised together with a lack of funding for services providing support to live independently once people moved in their houses.

*"It's not just about getting the house but also about the support and get once you're there."*

*"The hardest thing is getting the budget from the service and moving on for a better supporter. The institution don't want to lose that."*

*"It was the packing that I found hard. Getting all my stuff together from one house to another house. And then what I found hard was the bills that had to be paid, my shopping."*

*"I find it hard to keeping up with tasks everyday."*

### Lack of Control & Limited Social Interaction

It can be very difficult to adapt to a housing transition without having the formal and informal support needed to develop independent living skills such as cooking, paying bills, and cleaning. When formal support is provided, sometimes it is not respectful of the person's will and preferences.

*"I feel like I lost my independence during covid."*

*"I want to be more included in decisions about my house."*

*"When there is not transport you are depending on family for lifts for you getting to and from places."*

*"I miss my family here."*

*"I would like somebody to talk to."*

## How can we improve things in housing?

### Increase House Availability

Participants highlighted the need to build more accessible and modern houses in the city or in areas that are well-connected to transport and normal community services such as shops and social centres. They would like to see the county councils and the government providing more options to live independently.

*"More housing for people with disabilities (more funding), more accessible transport services (especially in rural areas)."*

*"System needs to change and to be fresh so that people can have the options they want to live independently."*

### Affordability

Policies should also change to make it easier for people with disabilities to buy a house or get personal and financial support to live on their own.

*"Change policies to make it easier for people with disabilities to buy a home."*

*"Government should provide funding for individuals who need housing support to promote independent living."*

### Accessibility

Accessibility was raised as a main issue by participants. From making the application for housing to the house itself and its location, many obstacles make it very hard to achieve a basis for independent living.

*"The application for supports to live in your own home is broken, people do not know how to apply, it needs to be fixed in a nationally uniform manner. We also need to collect data on housing and support lists so they may be addressed."*

*"We need accessible housing in towns and cities."*

*"Access to transport has to be provided to increase independent living."*

### Support and Self-Determination

People should be able to choose the support they want and be empowered to make their own decisions: where to live, with who and how. It is crucial for people to be supported to live independently, especially after they have moved in. This not only involves training and support for basic household tasks but also engagement within their community. The support should not interfere with people's self-determination and the way they want to live their lives. Assistive technology has been pointed out as particularly important in enabling people with higher support needs to live independently.

*"Choosing the support you need, not everyone needs the same support."*

*"I would like to be more involved in the rules."*

*"More choice in location and people you live with. Being able to live near people you want to live with."*

*"Get to do my own shopping, cooking and have my own peace and quiet."*

*"What I would like to see is people deciding what they want. Because at the end of the day, it's an adult service."*

*"It is important to learn new tasks or how to use appliances independently."*

*"Engage with your community and support each other to live independently."*

*"Support independent lifestyle, more key workers, let us reach our potential."*



## Social Life

Finally, participants discussed the necessity to engage with the community, to meet new people outside and to have other people over to visit.

*Feeling safe in your community is important.*

*Have people over to visit – have dinner with someone to combat loneliness.*

*I want to be able to relax with family without them being responsible for caring.*



# 7

## Personal Choices and Relationships

“Eliminate discrimination in all matters relating to marriage, family, parenthood and relationships.”

**Article 19 UNCRPD**



# 7

## Personal Choices and Relationships

Article 12 - Equal recognition before the law

Article 22 - Respect for privacy

Article 23 - Respect for home and the family



[CLICK FOR LINKS](#)

### Context in Ireland

The Assisted Decision-Making (Capacity) Act 2015 transformed Ireland's capacity and decision-making legislation, but it has yet to be fully commenced.

The Act provides for the presumption of capacity and the promotion of a person's will and preference and introduces a functional assessment of capacity. The Act sets out three legally recognised forms of supported decision-making. These are a decision-making assistant, co-decision maker, and a decision-making representative.

One key factor in bringing the ADM Act fully into law is the establishment of the Decision Support Service (DSS). Although the DSS was established in October 2017, progress in resourcing it has been slow. It is now expected that the service will start running from June 2022.

As the ADM Act has yet to be fully brought into law, people whose capacity is under question do not yet have a presumption of capacity when they interact with the Irish legal system. Currently, the Lunacy Regulation (Ireland) Act 1871 is still being used to receive people into wardship in Ireland.

The Mental Health Commission have stated that over 1,250 people have been made wards of court up to 2018 since the Act was passed. The Commission also commented that the ongoing effect of not commencing the act is that "hundreds of people continue to be taken into wardship, thousands of people remain vulnerable to financial and other forms of abuse and hundreds of thousands of people lack the formal frameworks to plan ahead, and to be supported to the fullest extent to make decisions about their own lives." <sup>22</sup>



<sup>22</sup> Mental Health Commission Annual Report 2019 p.44

## What is not right about our power to make choices?

### Negative Perception

Participants talked about the negative perceptions of people with intellectual disabilities by the general population, and the common assumption that they can't be independent and make decisions and choices for themselves. Individuals sometimes feel that they must conceal intimate personal relationships from their service and their families.

*"There is a generalisation about people with disabilities that they cannot make personal choices."*

*"Our opinions aren't always seen as equal."*

*"Individuals are not treating fairly other individuals who need extra support or assistance."*

*"It feels like relationships need to be hidden outside of the services."*

### Lack of Control

Many felt that they lack control over decisions that are effectively made for them by families and professionals. From simple decisions like going to the shop to important ones like getting married, they spoke about the culture of overprotection and the lack of opportunities to make mistakes and learn from them, like everyone else. Rather than getting the support they need to make decisions, decisions are often made for them on a regular basis.

*"There's all these rules that don't really work for us like we're not allowed to cut the grass, we're not allowed to hang up a picture. The way it's set up is like you live in your bedroom and there's a sitting room but you don't really use it. So it's not like living with friends."*

*"Sometimes we don't get to make choices – choices are made for us".*

*"Family limits choices. It feels like my life is somewhat controlled."*

*"Families can be overprotective."*

*"I know mommy and daddy are brilliant, but sometimes I want to do things on my own."*

*"We don't always have the support we need to make our own decisions."*

*"We are more controlled: e.g. family members restrict us by not letting us go to the shop by ourselves when we are able to."*

*"Not all parents really want their children to grow up and have a boyfriend or a girlfriend or be in a relationship. I know why they do it to protect us. But I don't like it because that's all important stuff to learn how to deal with and how to talk about."*

*"Independence is often taken away from individuals who need support/ assistance."*

*"People with disabilities are not able to make mistakes in relation to issues."*

*"Family and Services can be extra cautious with regards to seeing friends which can negatively affect the service users."*

### Covid 19

The Covid 19 pandemic posed a real challenge for some participants in maintaining their relationships, social interactions and independence.

*"Hard to meet people during Covid- but still trying to get involved and back into your community."*

*"Travelling the distance to meet friends etc. can be challenging due to lack of transport and Covid."*

## How can we improve things about making choices?

### Improve Perception

Raising the awareness of the general population, professionals, and families is important to address the negative stereotypes that prevent people from making decisions and having the relationships that they want. People should be assumed to have the capacity to make decisions for themselves.

*"Attitudes need to be changed in society, including family members who can be overprotective, services and the general public around decision making."*

*"Self-advocacy needs to be funded to help change public attitudes as people with disabilities are well capable of making many decisions. Risk in choices must be respected."*

*"We need more understanding from families."*

### More Control

More control should be given to people with disabilities about the choices they make such as: choosing their own relationship and friendships; being able to get married and have children if they want to; organise their day and activities in the way they intend to. It also means allowing them to take more risks and make their own mistakes like everyone else.

*"Everyone should have the right to make their own decisions, be listened to, to have friends, relationships, and to control our own future."*

*"Having the choice of choosing your own relationships-friendships."*

*"Having a relationship and being able to get married and have children (without being scared of them being taken from you)."*

*"Getting to do things around the house-cooking your own food and having the choice on what to buy, eat etc."*

*"Get to do things they would like to do like driving or getting married by making own choices."*

*"Allow more people to take risks."*

*"Let people make their own mistakes so they can use it as an opportunity to learn."*

*"It is important to be able to make bad choices as well as good ones."*

*"The government should make policies to let people who need special support get married."*

*"Let people make their own decisions, give them support and the information they need to make decisions."*

*"We are enthusiastic to meet new people if we have the opportunity. It would make it easier if individuals could meet up with other individuals with the same interests to help form new relationships."*

### More Independence

*"More buses and modes of transport. More security when going out on transport- have to be careful."*

*"Living independently allows you to make choices."*

*"Remaining independent but still being able to access support when needed."*

*"Assisted decision making act needs to be implemented."*

### Better Support

Good support and encouragement from families and services is essential to build confidence in the development of independent living and decision-making skills.

*"Having the choice and being supported to do what you want - going to the cinema, pub for drinks etc."*

*"Rather than person influencing your decision they could give you information to help make the decision."*

*"We need staff to support us to make decisions."*



*"There are programmes like 'The National Autistic Society based in London' ..even though it is still very limited. These programmes help individuals with a need of special support to get the support to learn how to become independent."*

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*"Dating services should be more accessible".*

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*"I would like to get more support in self-confidence building and relationships."*

## **More Privacy**

*"Having privacy- having your own personal space and privacy, you don't want people listening to your private info."*

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*"Able to contact their partner over the phone."*



ice

Checking a Public Service for Accessibility

Your Rights and the Public Sector Duty

What is the Public Sector Duty?

Poverty AND Disability

Key steps to make public services accessible

ice



A close-up photograph of a man with short, light-colored hair and glasses, speaking into a black microphone. He is wearing a blue and white striped shirt under a dark sweater with red and grey horizontal stripes. The background is dark and out of focus. The number 8 is centered at the top in a white circle.

# 8

## Speaking up for Yourself

“Ensure effective and full participation  
in political and public life.”

**Article 29 UNCRPD**

# 8

## Speaking up for Yourself

Article 4.3 - General obligation - Participation

Article 21 - Freedom of expression and opinion, and access to information

Article 29 - Participation in political and public life

Article 33 - National implementation and monitoring



[CLICK FOR LINKS](#)

### Context in Ireland

The NDIS 2017-2021 highlights the need for public bodies and agencies to actively engage people with disabilities through consultative committees or other appropriate platforms at different decision-making stages: planning, design, delivery and evaluation of public services.<sup>23</sup> In particular, the strategy talks about “embedding a culture and process of early engagement with people with disabilities in mainstream service design and evaluation”.

The Department of Health and the HSE has a growing commitment to the active participation of people with disabilities in service evaluation and design. Transforming Lives is the name given to the process of reform of HSE-funded Disability Services in Ireland, and the Working Group on Service user and community involvement, produced a plan and guide for *Effective Participation in Decision-Making by people with disabilities*<sup>24</sup>. This plan was launched by the junior Minister with responsibility for Disability in 2018. Progress on implementing this plan is slow but there is some evidence of commitment to follow-through.

The 2012 New Directions policy for HSE funded Day Services has a specific commitment to engaging people supported by services in the development of policy and practice. As noted above, delivering on this commitment in the implementation of the interim standards for New Directions, has been identified as a significant challenge by service providers.

Section 42 of the Irish Human Rights and Equality Act 2014, places a statutory obligation on public bodies to eliminate discrimination, promote equality of opportunity and protect the human rights of staff and the public who use their services. This is commonly known as the “Public Sector Duty” and it requires public bodies to regularly review their performance in respect of these obligations by using an “assess, address, report” approach.

In principle this gives disabled people the opportunity to report any discrimination that they encounter in accessing public services and to seek the development of actions to address these issues. The active implementation of the Public Sector Duty within public services has been slow to gather momentum, but there is evidence of good practice slowly beginning to emerge within some public bodies<sup>25</sup>.

<sup>23</sup> National Disability Inclusion Strategy 2017-2021, 2- Joined up policies and public services.

<sup>24</sup> [Effective Participation in Decision-Making](#)

<sup>25</sup> [Implementing the Duty: Pilot Case Studies](#)



[CLICK FOR LINKS](#)

## What is hard about speaking up for yourself?

### Lack of Awareness and Respect

Self-advocates pointed out that, in their experience, the views of people with an intellectual disability are often not encouraged, valued, or respected within the wider community.

*"There isn't a willingness to listen to us"*

*"Our voice isn't being heard"*

*"People focus more on our disability rather than our ability to do things"*

### Lack of Confidence

Due to this negative perception within the wider community, many people with an intellectual disability lack the encouragement and confidence that they need to advocate for themselves. People who have had negative experiences such as bullying and institutional abuse, also find it harder to speak up for themselves, and may be fearful of doing this. It can be particularly challenging for people with high support needs to have their will and preferences acknowledged and respected.

*"Some of us individuals can get nervous/ anxious about speaking up for ourselves."*

*"Afraid to speak out as our intentions don't always be taken seriously."*

### Lack of Information

Many participants explained that they are not fully aware of what their rights are, and they don't know how to complain. There is a lack of awareness of the existing tools/remedies. This is also often true for supporters and family members of people with an intellectual disability.

### Lack of Control

It is not unusual for people with an intellectual disability to feel that they do not have the possibility of making their own life choices and that most of the decisions about their lives are made by others. It was pointed out more specifically that the UNCRPD Optional Protocol has not been ratified and this limits the opportunities to make complaints. The lack of representation of people with an intellectual disability on the boards of service providers was highlighted as an indicator of their exclusion from decision-making.

*"Sometimes we can be stopped or talked out of specific actions we want to take e.g. going to the shop by ourselves, traveling to specific destinations"*

*"People taking away your voice saying 'this is what you should do.'"*

*"No clear pathway of how to be heard by people that make the decisions."*

*"Not enough people with disability on the disability board."*



## How can we improve things?

### Importance of Self-Advocacy

Participants underlined the importance of self-advocacy and how they wanted the opportunity to be seen and heard like everyone else, particularly by decision-makers and the government.

*"You have to speak until they listen to you."*

### More Acceptance/Less Judgement

Everyone has the right to be heard and people need to speak up for themselves without feeling that they will be judged. People should show more respect towards people with disabilities and the government has to play a role in promoting self-advocacy. This is an essential part of a national recognition of the need for equal rights.

*"As people we have rights – we are who are. We cannot change so we might need support to speak up and be listened to."*

### Better Representation

In the same way that there is a quota for women, participants thought that there should be one for people with intellectual disabilities. People with an intellectual disability should be supported to be involved in decision-making within publicly funded services and decision-making bodies. Their experience and expertise should be respected and important decisions should not be made without their input.

*"We want people with disabilities to be on boards of services and also to understand and be a part of government Committees. To do this training is very important"*


*"We should have more meetings with government so they take our voices seriously, they should communicate in a way that suits disabled people."*

### Better Support/Tools

Training, support and encouragement should be available for people who want to get involved in self-advocacy. A state funded mechanism could support the development of a strong self-advocacy movement. People with high support needs who cannot communicate verbally, should be facilitated to communicate their will and preference with the support of family members and advocates.

*"We need supporters to support us to do what we want to do."*

*"The right to freedom- we should be able to do what we want to do without being stopped or talked out of it."*

A woman with short, curly brown hair and glasses is speaking and pointing her right index finger upwards. She is wearing a purple collared shirt under a dark blue sweater with a beaded necklace. In the background, a man with short dark hair is looking down, and a woman with blonde hair is looking towards the speaker. They are in a room with large windows showing a landscape.

## Recommendations

“People supported by services, need to have more control over the support that they get and the range of activities that this support enables.”

# Recommendations

## Accessibility and Awareness Raising

- There should be national awareness raising initiatives that target the general population (e.g. a disability month)
- Specific training should be provided to professionals working with people with disabilities both in terms of awareness-raising and accessibility
- There should be a specific awareness raising focus on improving access to information and communications
- Accessible public transport levels should be increased, particularly in rural areas and all information about public transport should be accessible.

## Inclusive Education

- More awareness-raising training should be provided to students within schools and there should be better training for teachers in disability awareness
- In line with the UNCRPD, disabled people should be included in mainstream schools
- School-based supports should be significantly increased in areas such as: Special Needs Assistants, school-based mental health units, school-based speech and language therapy
- There should be more support for learners with disabilities to develop essential social and independent living skills.
- For people who are still in special schools, there is a need for more choice of subjects, better access to leaving certificate exams, and access to career guidance.

## Day Services

- People supported by services, need to have more control over the support that they get and the range of activities that this support enables.
- The voice and aspirations of each person who is supported must be clearly reflected in their Person Centred Plan (PCP), and these plans must be well facilitated, regularly reviewed and respected.
- The level of support should be increased, more personalised, and focused on specific personal interests. Support should not be restricted to 10-4 on a Monday to Friday and it should include the possibility of work experience and more community-based social activities in the community.

## Employment

- The state needs to raise awareness amongst people with intellectual disabilities and employers about existing schemes and supports that facilitate access to employment.
- Accessible information about employment-related supports for people with intellectual disabilities should be made available and disseminated widely
- The state should mainstream supports that enable people with intellectual disabilities to take up and maintain paid employment, for example by providing funding for job coaches.
- Employers from the private and public sector should have easy access to information and training that encourages them to employ people with intellectual disabilities
- Transport services should facilitate access to employment for people with an intellectual disability.

## Independent living and housing

- A central, accessible application process for people to apply for independent living support must be developed
- Government must resource the HSE to provide additional support packages to enable disabled people to live independently such as personal assistance, home help or other independent living supports.
- A clear and robust assessment tool for personal budgets and independent living support must be applied with the disabled person fully involved and engaged.
- Capacity building must be made available to individuals who require it to support their independent living. This should include, managing a home budget, home maintenance, community inclusion, using transport, etc.
- A disabled person should be able to access supports to live independently regardless of their level of impairment or support need once they reach the top of the housing list.
- People not currently receiving a HSE service should be able to apply for a personalised budget to live independently.
- Greater use of personalised budgets must be made available to support independent living.
- Assistive technology should be provided to make it easier to live independently, especially for people with higher support needs.
- The state should resource extensive education and awareness-raising about the value and importance of self-determination for people with intellectual disabilities.
- State funded support services should facilitate more freedom and choice for the people that they support. Positive risk-taking should be encouraged, including the right to make mistakes.
- State-funded support services should be supportive of the formation of intimate personal relationships by people with an intellectual disability.

## Participation in Public and Political Life

People with intellectual disabilities have to be seen as equal citizens with an equal right to take part in public and political matters of their community.

- State agencies should resource self-advocacy both in terms of funding to build capacity and in terms of facilitating accessible participation in consultation and decision-making processes.
- Information and communications by state-funded agencies should be available in a format that is fully accessible to people with an intellectual disability
- There should be better representation of people with intellectual disabilities in leadership positions: boards, advisory and decision-making bodies, political structures.

## Personal Choices and Relationships

In line with the principles of the Assisted Decision-Making (Capacity) Act 2015, everyone must be presumed to have the capacity to make their own decisions.

- The Assisted Decision-Making (Capacity) Act 2015 must be fully commenced.



## Inclusion – Ireland

### Outing and Connecting

ard

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## Conclusion

“These consultations showed us that there is a real hunger for change and a great potential for leadership within the community of people with an intellectual disability.”

## Conclusion

***The people with intellectual disabilities who took part in this consultation spent a lot of time preparing for the events in their local advocacy groups. They spoke passionately about a lack of control over many aspects of their lives. They had a strong sense that their opinions often are not valued and do not matter.***

There was a great buzz during the consultations. People were energised by the opportunity to talk about what their lives were like and the changes they would like to see. They wanted to have their voices heard. It was particularly powerful that these consultations were led and facilitated by people with an intellectual disability. This created a sense of leadership and strengthened a belief in the possibility of change.

These consultations showed us that there is a real hunger for change and a great potential for leadership within the community of people with an intellectual disability. We hope and expect that the publication of this report is an important step in supporting the emergence of that leadership, and enabling their active participation in driving that change.

## Steering Group Members

### Claire Nagle

My name is Claire Nagle, I am very outgoing and enjoy getting out. I love walking and meeting people. I am a very confident person and honest and love the craic.

I live independently in my own apartment, and I am absolutely loving it, I receive support from the organisation Brothers of Charity. I have an amazing group who work with me and a good relationship.

I am the chairperson for the Clare platform, I have been involved in advocacy for very long time, it has taught me so much and built my confidence. In my role as chairperson, it has been a huge experience for me to help all the advocates the best way I could. Advocacy is so important and has made me a very strong person.



### David Leigh

My name is David Leigh I come from Baltinglass in County Wicklow I am a self-advocate in my local services where I go. I enjoy doing horse riding, watching TV, playing my play station. I love listening to my favourite music - my favourites are: The High Kings, Wolfe Tones, Christy Moore and Garth Brooks.

I also play bodhran and box drum and I love doing DJ in my community. I love my sports. I follow Liverpool in soccer. In GAA I follow Wicklow, my county football team. I also like the Dublin football team and I love playing darts.



### Margaret Turley

My name is Margaret Turley I am involved in a lot of projects mostly about rights for people with intellectual disabilities as I have a mild intellectual disability myself. I am also working with EY part time. On my down time I like to train and keep fit for my basketball.





## Tomás Murphy

My name is Tomás Murphy. I am one of the members of Inclusion Ireland UNCRPD Group. Before this, I have had experience of working with Inclusion Ireland on three research projects: 19 Stories of Social Inclusion in Ireland: Stories of Belonging Contributing and Connecting; Education, Behaviour and Exclusion; The Experiences of Adults with Intellectual Disabilities in Ireland During the Covid 19 Crisis. As part of this work I received a Certificate in Research.

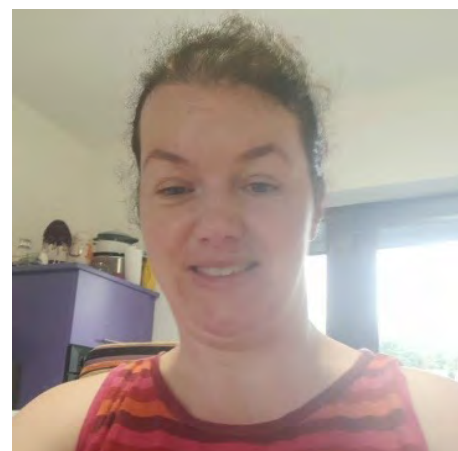
I also work for A& L Goodbody two days a week and I am on the A&L Goodbody Disability Committee.



## Aoife

My name is Aoife. I am a member of the Roscommon Harriers and I run twice a week. I do 5km races. I do mindfulness for ten minutes a day to relax the mind. I do daily walks in my centre. I do art in my centre. I go spinning twice a week in Snapfit. I go to music therapy in my day service. I go swimming with my centre on Wednesdays and I go independently in the evenings.

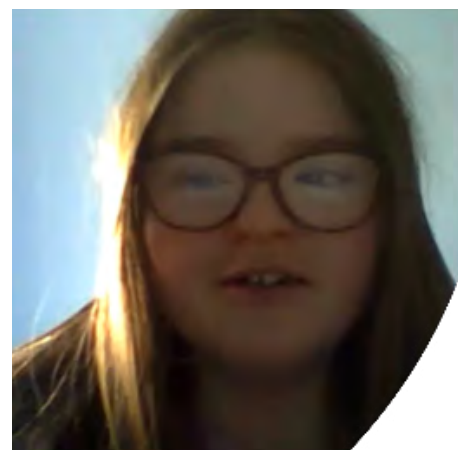
I am the chairperson of the Roscommon advocacy group. I represent people and speak up for people's rights. I speak at conferences. I work every Monday Tuesday Thursday & Friday in Gleasons restaurant.



## Laura

My name is Laura. I live in Cork and I go to my day service with Cope Foundation. I do online yoga.

I speak at conferences on disability and work in the Mercy hospital. I take part in staff training to raise-awareness around disabilities. In 2014, I was in a documentary made by TV3 called my extra-chromosome and me. I was elected to the Student Council at school to make sure student's voices were heard. I was also a part of the green school Committee. In 2018, I spoke to the UCC students about my disability, it was called: My life with Down Syndrome.





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Special thanks go to the Steering group members for their time, commitment, and invaluable work in making the videos, and in the planning and delivery of the consultation events.

Thanks also to the self-advocacy group facilitators who facilitated great discussions within their groups and supported the participation of self-advocates at the consultation events. Thanks also to the advocates, staff and students from St John of God services who provided additional support during the consultation events.

Finally, we would like to thank all of those who attended the events, for the views and insights that they expressed, about the challenging experience of being a person with an intellectual disability in Ireland today.

Inclusion Ireland receives funding from Government through the Scheme to Support National Organisations, administered by Pobal to do this work.



Rialtas na hÉireann  
Government of Ireland



Coimisiún na hÉireann um Chearta  
an Duine agus Comhionannas  
Irish Human Rights and Equality Commission



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