**Disabled Peoples Organisation (DPO) Coalition**

**Consultation Report**

May 2023

The views and lived experience of disabled people in Ireland in response to the UN Convention on the Rights of Persons with Disabilities

| Almost 700 voices

| Many insights

| Concrete recommendations

# Why read this report?

This Consultation Report presents the views and experiences of disabled people in Ireland based on 672 surveys and 8 focus groups.

This Consultation Report was created in advance of the Irish Government presenting to the United Nations Committee on the Government’s work to implement the Convention on the Rights of Persons with Disabilities (UN CRPD).

In this way, this Consultation Report may act as a source of information to help create an Alternative Report in contrast to the Government’s Report.

The Consultation Report provides information and insights into the lives of disabled people. Many of these are worrying such as lack of access to essential services, healthcare and public buildings.

It also presents clear actions Government can focus on to improve disabled people’s lives and enable disabled people to participate fully in society.

**What this report is not**

This report is not a policy. It is instead real information and recommendations that can be used to create policy.

**What it includes**

**Chapter 1: Background to this Consultation Report**

**Chapter 2: Issues of Global Concern and Priority Areas of Action**

**Chapter 3: Survey Results – Key Findings on Lived Experience**

**Chapter 4: Focus Group Results**

Contents

[Why read this report? 2](#_Toc107847828)

[Acknowledgements 4](#_Toc107847829)

[**Chapter 1: Background to this Consultation Report** 5](#_Toc107847830)

[What is the UN CRPD? 5](#_Toc107847831)

[Who is the DPO Coalition? 5](#_Toc107847832)

[What is the DPO’s response to the UN CRPD? 5](#_Toc107847833)

[About this Consultation Report 7](#_Toc107847834)

[The Consultation Process 7](#_Toc107847835)

[A note on the words we use 9](#_Toc107847836)

[**Chapter 2: Issues of Global Concern and Priority Areas of Action** 11](#_Toc107847837)

[Moving away from a medical model to a social model of disability 11](#_Toc107847838)

[Priority Areas for Action 12](#_Toc107847839)

[**Chapter 3: Survey Results – Key Findings on Lived Experience** 18](#_Toc107847840)

[About this section 18](#_Toc107847841)

[Overview of findings 18](#_Toc107847842)

[Awareness and understanding 18](#_Toc107847843)

[Who took part in the survey? 19](#_Toc107847844)

[Findings in detail: 21](#_Toc107847845)

[Rights awareness 21](#_Toc107847846)

[Healthcare 22](#_Toc107847847)

[Access 22](#_Toc107847848)

[Not being listened to or understood 22](#_Toc107847849)

[Supports 24](#_Toc107847850)

[Work and employment 25](#_Toc107847851)

[Financial insecurity 26](#_Toc107847852)

[Education and training 27](#_Toc107847853)

[Safety from abuse 28](#_Toc107847854)

[Transport and accessibility in public 30](#_Toc107847855)

[Choosing where to live 31](#_Toc107847856)

[Social participation 32](#_Toc107847857)

[Participation in public and political life 33](#_Toc107847858)

[The UN CRPD in Ireland 33](#_Toc107847859)

[**Chapter 4: Focus Group Results** 34](#_Toc107847860)

[About this section 34](#_Toc107847861)

[How can public bodies realise the rights of disabled people? 34](#_Toc107847862)

[How can the Public Sector Equality & Human Rights Duty extend the realisation of rights? 35](#_Toc107847863)

[Optional Protocol to the UN CRPD 37](#_Toc107847864)

[Government action in realising rights 38](#_Toc107847865)

[Legislation and its effectiveness 39](#_Toc107847866)

[The UN CRPD and statutory bodies 40](#_Toc107847867)

[Role of the DPO Coalition 41](#_Toc107847868)

## Acknowledgements

The DPO Coalition Editorial Committee acknowledges with thanks the people who completed the survey and participated in the focus group discussions. The DPO Coalition Editorial Group also acknowledges with thanks, Dr Lucy Michael and Ms Alice Griffin, Project Consultants, with Dr Niloufar Omidi, for drafting this report, for and on behalf of, the DPO Coalition.

# Chapter 1: Background to this Consultation Report

## What is the UN CRPD?

The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) is a human rights treaty adopted by the UN in 2006. The Irish Government ratified the UN CRPD in 2018 and in doing so committed to promoting and protecting the rights of disabled people in Ireland.

All States that ratified the UN CRPD are obliged to submit regular reports to the UN Committee on the Rights of Persons with Disabilities (UN CRPD Committee) on how the rights of disabled people are being implemented. The Irish Government was due to submit its first report in April 2020 and was expected to appear before the UN CRPD Committee in late 2021 to speak about progress on implementing the UN CRPD. However, due to the impact of the coronavirus disease (Covid-19) this didn’t happen.

A draft Government Report was published in November 2020.The finished report was submitted to the UN CRPD Committee in November 2021.

## Who is the DPO Coalition?

The DPO Coalition is made up of national disabled people’s organisations in Ireland. Current members include:

* As I Am – Ireland's National Autism Advocacy Organisation
* Disabled Women of Ireland (DWI)
* Independent Living Movement Ireland (ILMI)
* Irish Deaf Society (IDS)
* National Platform of Self Advocates
* Voice of Vision Impairment (VVI)

## What is the DPO’s response to the UN CRPD?

The DPO Coalition came together to consult with disabled people before Ireland’s appearance at the UN CRPD Committee. It supported its members to identify key issues in advance of the UN CRPD Committee’s examination of Ireland and to prepare this Consultation Report.

This Consultation Report provides independent information collected on the lived experience and views of disabled people on the rights outlined in the Convention. The DPO Coalition’s approach ensures that people with direct and lived experience of disability help to create the consultation process and also create the ways disabled people participate in the consultation.

## About this Consultation Report

This report presents the findings and analysis from the DPO Coalition’s Survey and Focus Group Consultations held between March and June 2021.

This report is not intended to present policy recommendations. Instead, DPO Coalition members and others may wish to use this report to develop their own recommendations and to develop an Alternative Report, also known as a Shadow Report, which they can submit to the UN CRPD Committee. An alternative/shadow report is a report written by disabled people’s organisations or civil society groups which gives the UN CRPD Committee different information to what the State wrote in its report. It is important because it gives the UN CRPD Committee more information on what is happening on the ground.

It should be noted that disabled children and young people were not included in the consultation process. The DPO Coalition is committed to ensuring the voices of disabled children and young people are heard and that they are enabled to participate however due to time limitations and the lack of opportunities for in-person engagement, it was not possible to include them in this process.

## The Consultation Process

There were 2 parts to the consultation process:

1. Surveys – research to gather a lot of data

2. Focus groups – discussions to learn about people’s experiences

The aim of both the survey and the focus groups was to give DPO Coalition members the opportunity to share their experiences and opinions of being disabled in Ireland

**Surveys**

The DPO Coalition developed the survey questions based on input from stakeholders’ views at webinars as well as a themed approach to the consultation. The themes agreed included: Education, Employment, Inclusion and Independent living.

Each DPO Coalition member promoted and shared the survey with their networks and supported their members to complete it as far as possible. We provided surveys in plain English and surveys for Irish Sign Language users.

**How many surveys were completed?**

In total, 672 surveys were completed. These included:

* 284 Irish Sign Language surveys
* 42 plain English surveys

There were:

* 41 closed questions (questions that required yes or no answers and most always included ‘other’ options)
* 4 open questions (where participants could write in their own views)
* 31 opportunities to provide comment.

This produced 28,580 pieces of data to analyse.

**Focus groups**

The focus groups took place from May to June 2021. There were 8 focus groups with 63 participants in all. Each focus grouped lasted for 90 minutes.

The focus groups were made up:

* DPO Coalition members
* The DPO Coalition Steering Committee
* Parents/guardians of disabled children.

The focus groups allowed participants to share their experiences and opinions about issues affecting them. Participants received a list of questions to consider before the discussions. We developed these questions based on the survey results that were agreed with the DPO Coalition Editorial Committee.

For more detail, see Chapter 3.

## A note on the words we use

The DPO Coalition is committed to the human rights and social models of disability. The **social model of disability** says that the exclusion, inequality and discrimination experienced by disabled people are not the consequences of impairment, but instead are the result of the economic, cultural, social and political barriers operating in society. The **human rights model** builds on the social model by acknowledging disabled people as rights-holders and treats barriers in society as discriminatory.

In this report, the DPO Coalition uses **identity first language (IFL).** (“a disabled person”) rather than person first language (“a person with a disability”). IFL refers to a person with their condition listed first, for example, a Deaf person or an autistic person. It is used by disabled people to convey the importance of disability experience and identity.

**Disabled person**

We use the term ‘disabled person’ to acknowledge society’s role in disabling people. In other words, disability is something that happens when people with impairments face barriers in society. It is society that disables, not an individual’s impairment.

**Deaf people**

We use the word Deaf with a capital ‘D’, to refer to people who self-identify as culturally Deaf, and whose preferred language is Irish Sign Language (ISL). Deaf as a term includes both Deaf and hard of hearing signers. This study is not representative of the wider deaf and hard of hearing population who become deafened during their lifetime and who do not sign in ISL.

**Neurodivergent people**

We use the term “neurodivergent” to describe people whose brain differences affect how their brain works. That means they have different strengths and challenges from people whose brains don’t have those differences.

**Other words used in this report**

**Article**: A numbered section of a legal document such as the UN CRPD. For example, Article 7 of the UN CRPD is about disabled children.

**Gender sensitive services**: Services that are sensitive to people’s individual gender identities and sexual preferences.

**General Comment**: A document explaining the content of one or more articles in the UN CRPD and how they should be implemented by governments. General Comment 3, for example, is about the rights of disabled women and children.

**Medical Model**: Sees disabled people disability as being broken and incapable of fitting into society unless ‘cured’ or ‘fixed’.

**Optional Protocol**: An extra agreement to the UN CRPD which allows individuals to make a complaint to the UN CRPD Committee.

**Reasonable Accommodation**: Necessary changes to a practice, programme or physical environment so that it is accessible and usable by a disabled person.

**Key point**

In each of the four chapters in this report, we present the a key point in a statement like this one.

# Chapter 2: Issues of Global Concern and Priority Areas of Action

## Moving away from a medical model to a social model of disability

## 

**What are the human rights and social models of disability?**

The human rights model of disability changes how disabled people are viewed and treated. It is based on basic human rights principles recognising that disability is a natural part of human diversity that must be respected and supported in all its forms.

Disabled people are not “objects” of charity, medical treatment and social protection. Instead, disabled people are “subjects”, that is people who have rights and:

* Can claim those rights
* Can make decisions for their own lives based on their free and informed consent
* Are active members of society.

This model builds on the social model of disability which asserts that people are disabled by the environment they live in, and not by limitations of their own bodies. The social model does not deny the reality of impairment nor its impact on the individual. However, similar to the human rights model of disability, it does challenge society to see impairment as part of human diversity.

The social model of disability plays an important role in advancing the rights of disabled people by recognising that society as a whole is responsible for enabling inclusion.

**Why are the human rights and social models of disability important?**

The UN CRPD marks the official shift towards the social model of disability becoming the internationally recognised way to view and address ‘disability’. It will change current attitudes towards people with disability and approaches to disability concerns.

Currently, Irish law and policy is overwhelmingly based in a medical model of disability, with charitable and supplementary measures to address need, rather than a rights-based approach. Irish society must adopt the social model across legislation, policy and decision-making to implement the UN CRPD fully.

## Priority Areas for Action

**About this section**

In this section, we look at 10 key articles of the UN CRPD and outline the issues facing disabled people in Ireland that need immediate action.

Participants identified the complaints they would raise if the Irish Government were to sign the Optional Protocol to the UN CRPD explained in Chapter 4. We used that information to inform these points.

**Article 4.3**

Closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations (Also Article 33 and General Comment No. 7).

**Key point**

Organisations of disabled people should be distinguished from organisations ‘for’ disabled people.

Consultation on issues relating to disabled people must be interpreted broadly, and include:

* Planning and designing of public places
* Transport
* Work conditions
* Healthcare settings
* Decision-making processes

We need to distinguish between:

* Organisations **of** disabled people advocating on their own behalf such as the DPOs
* Organisations **for** disabled people which provide services and/or advocate for disabled people such as Disability Federation of Ireland
* Civil society organisations such as the Children’s Rights Alliance

The Irish Government should clearly identify and give priority to the supporting capacity of organisations **of** disabled people and prioritise their contributions in decision making. (See also General Comment No. 7).

A register of DPOs will support the government to implement this article across government departments and organisations.

**Article 5: Equality and non-discrimination**

Disabled people must have access to ways to counter discrimination.

**Key point:** Remedies must be made accessible

This State must:

* Provide accessible information about anti-discrimination supports like the Workplace Relations Commission
* Provide free legal aid
* Acknowledge financial constraints on many disabled people

Article 9: Accessibility

**Key point:** Accessibility issues are common across public services**.**

Accessibility issues are common across public services and general society.

They can occur across physical environment, transportation and technology. The State must:

* Remove institutional and bureaucratic barriers to accessing services by providing Personal Assistance (PA), or Irish Sign Language (ISL) interpreters
* Acknowledge and respond to individuals’ communication support needs and preferences
* Enact regulations on designing accessible public places and transportation
* Provide information and materials in accessible formats

**Article 27** Right to work on an equal basis with others

**Key point:** Public sector employment targets must be met

The State must:

* Enable disabled people to counter employment discrimination
* Increase public awareness of disabled people’s capacity to work and right to reasonable accommodations
* Promote employment for disabled people
* Remove barriers to work, including financial penalties
* Meet public sector targets for employment

**Article 19** Living independently and being included in the community

**Key point:** Disabled people cannot exercise their right to live independently

The right to live independently is not equally available in Ireland, due to:

* Lack of in-home and community-based services
* Financial penalties for living with partners
* Lack of access to suitable housing

Personal Assistance (PA) availability and access to community facilities are key.

**Article 25** Health

**Key point:** Access to healthcare impacts on a wide range of other rights

Difficulties in accessing healthcare services remain the most challenging issues for disabled people in Ireland. This has a serious impact on disabled people being able to realise all their other rights.

To counter this, the State must:

* Provide affordable, equal and timely access to all healthcare services, and, in particular, to mental healthcare and reproductive healthcare
* Provide sexual and reproductive services and related information in accessible formats
* Remove physical barriers to access
* Facilitate access to gender-sensitive services, including health-related rehabilitation. Such services are sensitive to people’s individual gender identities and sexual preferences.
* Train and raise awareness among healthcare service providers and professionals about disability

**Article 30** Participation in cultural life, recreation, leisure and sport

There is low participation in many areas of life is due to:

* Accessibility issues
* Low public awareness of the supports available
* Low awareness from organisations of their responsibilities under the law to facilitate access for disabled people
* Absence of supports including Irish Sign Language

We need to raise awareness across society about inclusion, accessibility, the power of language and non-discrimination.

**Article 6 Disabled women**

**Key point:** Disabled women experience multiple forms of discrimination

Disabled women and girls are subject to multiple forms of discrimination in education, employment, healthcare services and experience antisocial behaviour in society.

The State must:

* Focus on full and equal participation of women in society through investing in their education and facilitating employment of disabled women
* Provide financial supports for disabled women who are parents and/or have caring responsibilities
* Provide effective supports for disabled women who are exposed to domestic violence, abuse and discrimination

**Article 7** Disabled children

**Article 24** Education

**Key point:** Childhood development and education are commonly delayed or denied

Disabled children experience exclusion and discrimination in the education system, lack access to information, and often have limited access to necessary therapeutic services and supports.

The State must:

* Remove institutional and bureaucratic barriers in diagnostic services and the assessment of need process
* Make it so that people do not have to be diagnosed to be able to access supports
* Help parents of disabled children find the services they need more easily
* Consult with disabled children and their parents

**Education**

* Train and raise awareness for teachers and other educational staff
* Provide educational materials in accessible formats
* Remove barriers limiting options in higher and further education
* Oblige providers to provide necessary supports and access to education
* Address barriers in access to technology for childhood development and education

**Article 13** Access to justice

Disabled people have little confidence in the legal and criminal justice system and relevant supports. This is due to lack of information for disabled people, and lack of awareness of disability and accessibility amongst legal professionals.

This can all result in discriminatory outcomes for disabled people engaging with the criminal system, including victims.

# **Chapter 3: Survey Results – Key Findings on Lived Experience**

## About this section

In this section, we discuss the survey result in an overview and then in detail. Survey participants were asked about their rights, their quality of life and their understanding of UN CRPD.

## Overview of findings

The findings highlight the following:

### Awareness and understanding

* Most survey participants (89%) believe that the general public do not have a good understanding of disability.
* Over half (56%) believe that healthcare workers do not understand their needs.
* 42% believe they do not have enough information about their rights under the UN CRPD.

**Discrimination and abuse**

**Key point:** Even those with good knowledge of their rights report having difficulty knowing how to exercise these rights

* 75% experienced discrimination because of their disability.
* 76% experienced violence or abuse because of their disability. Over half (51%) of the people who experienced violence or abuse reported difficulty in accessing the supports and services they needed afterwards.

**Access and participation**

* 67% have difficulty accessing healthcare they need.
* Over half (54%) believe that they do not have easy access to the same education and training opportunities as other people.
* 63% believe that there are difficulties accessing the same work and employment opportunities as other people.
* About a quarter (24%) have had difficulties in using their right to vote
* Almost two thirds (63%) reported that they only occasionally had access to the same social activities as non-disabled people.

**Finance and employment**

* 57% reported that they experienced financial insecurity because of disability.
* Nearly half (49%) believe that their current unemployment is related to their disability.
* 42% stated that their employer has not made reasonable accommodations for them.

## Who took part in the survey?

In total 672 surveys were completed by disabled people, including 284 people who used the Irish Sign Language surveys and 42 people who used the plain English surveys.

|  |  |
| --- | --- |
| **Age:** | 60% were 31-54 years old, 22% were under 30, and 19% were above 55. |
| **Gender:** | 69% reported their gender as female, 21% as male, 4% as Nonbinary, and less than 1% chose to self-describe in other ways.  Just under 3% described themselves as LGBTQI. |
| **Location:** | 22% were living in rural areas, while 33% were living within cities, and 41% within towns or villages. |
| **Living arrangements** | 69% reported living with their families, 16% living alone, 11% living with friends, housemates, or partners, and 1% in residential settings. |
| **Organisation:** | **Who did participants receive the survey from?**  38% Irish Deaf Society  32% Disabled Women Ireland  14% As I Am Ireland's National Autism Advocacy Organisation  11% Independent Living Movement Ireland  3% National Platform  2% Voice of Vision Impairment  Participants were able to tick more than one box. |
| **Disability:** | **What did participants report themselves as?**  39% Deaf and hard of hearing  31% with physical disability  26% with mental health conditions,  22% with neurodivergent conditions  8% with vision impairment  8% with learning difficulties  2% with intellectual disability  1% with acquired brain injury.  Participants were able to tick more than one box. |
| **Ethnic backgrounds:** | 65% of survey participants reported their ethnic backgrounds as white or white Irish background; 2% as mixed background; 1% as Black or Black Irish, and less than 1% as the Irish Traveller community and Roma. |

## Findings in detail:

## Rights awareness

Just over half (56%) of participants said they had good or very good understanding of their rights as disabled people. The majority of those who were confident about their rights reported that they learnt their rights through experience or working as activists or through higher level education. Additionally, even those who had good knowledge of their rights report having difficulty knowing how to navigate the bureaucratic system to exercise these rights.

**Challenge was to enforce rights**: The biggest challenge was the enforcement of these rights. Lack of access to Personal Assistance (PAs), and Irish Sign Language interpreters for the Deaf community limits access to supports and accurate information to exercise their rights. In particular, disabled women were concerned about their financial rights.

**Public lack of understanding of disability:** 89% of survey participants believe that the general public do not have a good understanding of disability. A particular lack of awareness was reported around invisible disabilities and mental health issues. Lack of understanding is seen in the planning and designing of public places that do not meet basic needs of disabled people.

**Discrimination:** 39% of participants regularly or often experience discrimination or unfair treatment, particularly disabled women and those from LGBTIA+ groups. Institutional and attitudinal discrimination against disabled people are common in workplaces, healthcare, education and leisure activities. Stigma around mental illness, dehumanisation, hate speech, disrespectful attitudes and bullying are reported as ongoing issues.

## Healthcare

### Access

67% of survey participants reported difficulties getting the healthcare that they need. Physical barriers include both difficulties in getting to the healthcare service centres and also the lack of necessary facilities within the centres.

The most significant institutional barriers for access include:

* Bureaucratic and procedural barriers
* Lack of sufficient specialists in some specific fields, especially in the public sector
* Lack of financial support
* Poor sharing of information
* Lack of timely access to essential instruments such as hearing aids

While difficulty in accessing healthcare services is widespread, physiotherapy services, mental health services, and sexual health services are even less accessible for disabled people.

### Not being listened to or understood

**Key point:** More than half don’t feel listened to by healthcare professionals and providers

56% of survey participants believe that healthcare service providers and professionals do not sufficiently listen and understand them especially when disabilities are hidden. Institutional barriers related to this include:

* Not enough time due to the overwhelmed system
* Lack of sufficient training for healthcare workers
* Inaccessible consent forms
* Lack of knowledge of cross cutting issues

Dismissive attitudes amongst professionals are reflected in:

* Disabled people having questions and experiences ignored
* Impatience with complex/multiple conditions
* Insulting and stressful consultations
* Discriminatory and racist attitudes
* Explanations not being in plain English with little effort made to ensure that they are understood

Particular healthcare issues affected some groups.

**Neurodivergent people** reported issues such as:

* Lack of access to specialists in public healthcare system
* Lack of understanding of different communication needs
* Lack of awareness of language processing issues
* Information retention issues associated with some neurodivergent conditions
* Difficulties in getting occupational therapy and psychological therapy

**The Deaf community** have serious difficulties accessing information, due to:

* Lack of access to interpreters and captions
* Lack of an accessible alternative communication method instead of the phone
* Medical professionals’ lack of awareness of Deaf people’s needs
* Violation of the right to privacy in instances where it is necessary to have a third person present
* Insufficient information in Irish Sign language (such as information on Fertility – IVF)

**Vision impaired people** are not provided withinformation in accessible formats such as Braille, screen reader friendly, large print and so on.

**Sexual health treatments for disabled people** continue to be dismissed by healthcare service providers and professionals. Additionally they have no access to their preferred contraception.

## Supports

**Key point**: More than 40% said they had no access to supports they need

42% of survey participants reported that they have no access to the supports they need such as disability payment supports, personal assistance, and mobility aids and assistive devices and technology. Only 19% feel they have good or very good access to supports.

There is a very low level of satisfaction across a wide range of disabilities. The people who were most satisfied with their access to supports were vision impaired people (28%) or people who are Deaf or hard of hearing (23%). All other groups were less than half as satisfied with their access to supports.

The main issues raised as difficulties in accessing supports were:

* Lack of access to Personal Assistance
* Unavailable medical supplies (for particular purposes such as IVF)
* Insufficient and unavailable mental health services
* Difficulties for neurodivergent people
* Unaffordable instruments such as hearing aids
* Limited disability allowance
* Systemic discrimination

## Work and employment

**Key point:** Nearly half of those unemployed believe their unemployment is related to their disability

63% of survey participants believe that have difficulties accessing the same work and employment opportunities as other people.

**Common issues accessing employment opportunities**

* Physically inaccessible workplaces and interview venues
* Lack of appropriate jobs for disabled people
* Attitudinal problems
* Institutional barriers
* Inaccessible information
* Communication barriers
* Financial issues

Only48% of survey participants were in paid employment at the time of the survey.

Of those unemployed, 49% believe that their current unemployment is related to disability.

The main reasons given for their unemployment were:

* Difficulties coping with the office environment
* Early retirement due to disability and illness
* Lack of job opportunities suitable for disabled people
* Losing the Disability Allowance when starting a job

72% of survey participants reported needing some reasonable accommodations at work. Of those that were in work, 42% said their employer had not made reasonable accommodations for them. They reported the lack of understanding of their needs, lack of awareness of reasonable accommodation and available sources.

Only 45% of those in work believed that they received the same pay and benefits as non-disabled colleagues. Others reported issues such as:

* Undervalued qualifications (leading to minimum wage employment)
* No promotion/no pay rise after many years
* Serious discrimination and abuse
* Reduced hours
* Reduced holidays and pension
* No extra pay for extra work
* No equal pay for equal work

**Common issues in work and employment**

* **Physical barriers** – Transportation, inaccessible buildings and so on
* **Nature of existing jobs** caused difficulties such as inflexible jobs
* **Attitudinal problems** – Dismissive and discriminative approach during interviews and in workplace, low interest in employing a disabled person
* **Institutional barriers** – Limited job opportunities, the lack of a disabled person-led support systems, lack of opportunity to develop and rise in positions, lack of a fair competition between disabled people and non-disabled peers in the job market
* **Dissemination of information** – Difficulties in accessing guidance about working hours, benefits
* **Financial** –Starting a job leads to losing the Disability Allowance

## Financial insecurity

**Key point:** Being disabled is expensive and disabled people commonly experience financial insecurity

57% of survey participants reported that they experienced financial insecurity because of disability in the last three years.

**Common reasons for experiencing financial insecurity were**:

* Limited Disability Allowance
* Fear of losing benefits when starting a job
* Unemployment due to discriminative recruitment
* Insecure temporary contracts
* Medical expenses related to impairment
* Cost of disability-related instruments and technology
* Lack of reasonable accommodations

Also, single parents and those who had caring responsibilities reported their financial challenges were due to the lack of financial support services for these groups.

Those survey participants with no financial issues reported that they had family supports and their expenses were covered by their parents or their partners.

## 

## Education and training

**Key point:** More than 50% said they cannot easily access equal education and training opportunities

54% of survey participants reported they cannot easily access the same education and training opportunities as other people. While physical barriers such as insufficient transportation and inaccessible buildings are distinctive issues, attitudinal, institutional and financial barriers were clearly highlighted.

Issues that continue for disabled people with different types of impairments were systemic unawareness of disability issues and lack of:

* Accessible information
* Access to assistive technology
* Reasonable accommodations

Among all these inequalities, participants highlighted inequality in access to higher education as one of the distinct points of discrimination

Physical barriers include:

* Inappropriate and unaffordable public transport especially in rural areas
* Inaccessible buildings with inappropriate design
* Insufficient equipment for disabled people

**Common issues include**:

* Difficulties in accessing Personal Assistance (PA)
* Lack of tutors with knowledge about disability and inclusive education
* Widespread discrimination
* Low expectations
* Financial problems
* Bureaucracy in disability services
* Inaccessible technology
* Restrictions on access to reasonable and affordable accommodation.

## Safety from abuse

**Key point:** Three-quarters had experienced violence or abuse in the last 3 years

Three-quarters (76%) of survey participants reported that they had experienced violence or abuse in the last three years. Half (51%) of those experiencing violence or abuse reported difficulty in accessing the support and services they needed afterwards. Only 23% of survey participants think that police, solicitors and court staff are trained to appropriately support disabled people.

There were six key institutional barriers to accessing support and services:

1. **Gardaí and legal bodies**

Dismissive approach by Gardaí, failure to investigate complaints and lack of support for victims of crime.

2. **Workplace**

Failure of workplace policies and procedures to ensure complaints were received and handled appropriately. Moreover, victims were discouraged from complaining and the focus was often on organisational risk rather than employees’ autonomy (independence) and dignity. Other failures included: illegal discrimination in the workplace, and the failure in public sector workplaces to implement the Public Sector Equality and Human Rights Duty.

3. **Schools**

Ineffective responses in schools to abuse.

4. **Support services**

Support services are based on a medical model of disability, lack of access for a range of disabled persons, failure to believe the victim in relation to abuse allegations, and low trust in services to respond.

5. **Counselling services**

Lack of access to counselling services for a range of disabled persons and insufficient training of therapists in relation to vulnerability.

6. **Local authorities and other bodies**

Failures to support disabled people by local authorities in relation to housing, and failures by other organisations dealing with homelessness, poverty and so on.

There were attitudinal barriers which prevented disabled people getting the support and services they needed. This was illustrated by:

* Stereotyping by service providers
* Emotional abuse
* Verbal and physical abuse
* Disrespect
* Undervaluing
* Undermining disabled people’s capacity for decision-making and action
* Not listening to or believing disabled people
* Lack of supports for those who are isolated.

There was low awareness of the nature of abuse, and

* How to report it
* How to access supports
* What can be understood as criminal assault, sexual assault, and abusive relationships.

Awareness about how to get support to leave abusive situations was low. Many people who reported being in abusive situations are reliant on family and friends to help them navigate towards information services, and advice aimed at disabled people is often silent on vulnerability to abuse.

Other reasons that prevent disabled people accessing supports and services were not having the confidence to report the abuse, the fear of being traumatised again and lack of trust in service providers.

## Transport and accessibility in public

**Key point**: Disabled people have little or only occasional access to public transport and public buildings

Participants highly rely on public transport due to not being able to drive and/or the cost of driving. Just over half (52%) had very little or occasional access to public transport.

In the survey, the decline of public transport in rural areas for disabled people is widely noted as a significant barrier to their participation in work, education, healthcare, and social activities.

There are also common issues in public transport, such as:

* Inaccessibility of stations and platforms
* Lack of on-demand assistance
* Failure of providers to meet statutory standards
* Long-term out-of-service equipment such as lifts, ramps, steps.

Disabled people’s ability to drive private vehicles is limited by:

* Low availability of adapted automatic vehicles (including suspended state grants)
* Poor access to the Primary Medical Certificate
* Not being able to travel to the city centre due traffic reduction measures.

Participants were asked about access to public and private buildings, for example, libraries, cafes, workplace and their friends’ homes. Almost half of participants described their access as very little or occasional, instead of regular or most of the time.

Physical barriers include:

* **Getting to buildings** – Public transport, poor pavement infrastructure, lack of accessible parking, and lack of signs.
* **Getting access into buildings** – Intercoms, stair-only access, and inaccessible entrances.
* **Inside buildings** – Absence of lifts, lack of space for wheelchairs, disabled facilities which are unusable (steep ramps, disabled toilets that are too narrow), lack of seating.
* **Sensory barriers** – Noise, bright lights, intercom or call systems and inability to use disability aids.
* **Staff in buildings** – Difficulties in accessing information and help inside buildings make it harder to access public spaces; being forgotten or ignored by staff in public buildings is a common experience.

Just over half (53%) of participants could not access information about public transport in accessible formats more than occasionally. This was the case for 70% of Irish Sign Language users, 60% of intellectually disabled people and 60% of vision impaired people.

## Choosing where to live

**Key point**: Choices of where to live are restricted by a wide variety of factors that specifically affect disabled people

One third of participants (34%) felt unable to choose where to live and who to live with.

Choices were limited by lack of access to a Personal Assistance (PA) or due to:

* Financial limits on living independently
* Housing discrimination
* Suitability of housing
* Access to transport
* Accessibility of local services and facilities
* Financial issues (in general, or such as losing benefits by living with partner)

A number of consequences of the restrictions on where and how disabled people live noted include:

* Decreasing mental health
* Decreasing physical health due to inaccessible facilities
* Isolation

## Social participation

**Key point:** Most disabled people only occasionally have access to the same social activities as non-disabled people

Almost two-thirds (63%) of participants reported that they only occasionally had access to the same social activities as non-disabled people. This was the case for 74% of Irish Sign Language users, 60% of physically disabled people, 55% of intellectually disabled people, and 44% of vision impaired people.

In addition to the general accessibility issues previously mentioned, participants were excluded by lack of information provided by community/social groups, low disability awareness in events organisation, and refusal of entry.

Just 39% of disabled participants felt included in their community regularly or often. 30% only felt involved occasionally, and 29% did not feel at all included.

Positive experiences were described in relation to increases in virtual meetings, and access to communities and information through social media.

Participants also described positive experiences in feeling included in:

* Volunteering work
* Local sports facilities
* Community development activities
* Children’s activities
* Local libraries
* Community groups
* Disabled-led groups.

## Participation in public and political life

**Key point:** Disabled people are excluded from political life both by physical barriers and information barriers

Nearly a quarter (24%) of participants have had difficulties in using their right to vote, due to accessibility issues (transport, building access), reliance on others to vote, lack of accessible pre-election information, and need for postal voting.

More than half (55%) have had difficulties contacting or meeting their political representatives. Accessibility issues also apply to constituency offices and lack of interpreters or digital aids.

## The UN CRPD in Ireland

**Key point:** Most disabled people believe that the implementation of UN CRPD in Ireland will improve their lives

Most participants (91%) believe that the UN CRPD will improve life for disabled people in Ireland either a little or a lot.

The signing of the Optional Protocol (discussed in Chapter 4) was mentioned by all groups as an essential factor in ensuring improvement of access to rights for disabled people.

More than half (58%) have some information on the UN CRPD, but a large minority (42%) believe they do not at all have enough information on their rights under the UNCRPD.

Ways in which the Convention can improve rights include:

* Representation of disabled people in planning/design (all areas)
* Implementation and compliance
* Consideration of disability as a rights issue by moving to the social model of disability

# **Chapter 4: Focus Group Results**

## About this section

In this section we outline how the focus groups took place, the 7 key questions/topics that were discussed and what emerged from the discussions.

Eight focus groups were held with 63 participant in total from:

* Representatives of each organisation in the DPO Coalition (6 focus groups)
  + As I Am – Ireland's National Autism Advocacy Organisation
  + Disabled Women Ireland (DWI)
  + Independent Living Movement Ireland (ILMI)
  + Irish Deaf Society (IDS)
  + National Platform of Self Advocates
  + Voice of Vision Impairment (VVI)
* The DPO Coalition Steering Committee (1 focus group)
* Parents/guardians of disabled children. (1 focus group).

## How can public bodies realise the rights of disabled people?

Participants suggested that public services could achieve equal treatment for disabled people by doing the following:

1. **Active involvement** – Disabled people must be involved in the planning and delivery of services to counter inaccessibility and inefficiency. Public services must also acknowledge ‘hidden’ disabilities.

2. **Training** – Public sector staff should receive disability and equality training.

3. **A change in attitude** –Public bodies must change their assumptions of disabled people as care receivers. Schools must raise their expectations of what disabled children can achieve in the education system.

4. **Remove barriers** –Systems must be more user friendly and understand and respect different or multiple identities. There must also be more training and dedicated budgets.

5. **Participation in policymaking** – Disabled people and their representative bodies must take part in policymaking processes and there must be opportunities for self-advocacy

6. **Inclusive communication and accessible information**. This can be addressed through:

* Acknowledging people’s different communication needs
* Using alternative and augmented communications (AAC) when it is preferred
* Ensuring websites, documents and forms are fully accessible and follow plain English and Easy-to-Read principles
* Committing to full implementation of the Irish Sign Language Act 2017 and guaranteeing access to Irish Sign Language interpretation

## How can the Public Sector Equality & Human Rights Duty extend the realisation of rights?

**What is the Public Sector Equality & Human Rights Duty?**

Under the law, all public bodies in Ireland must promote equality, prevent discrimination and protect the human rights of their employees, customers, service users and everyone affected by their policies and plans.

The majority of the focus group participants (65%) had heard of the Public Sector Duty & Human Rights (the Duty). Participants suggested that the Duty could be made an effective tool for realising rights if public bodies did the following:

**Funding**

* Acknowledge implementation costs
* Make it so that if organisations did not comply with the Duty, their funding might be affected
* Provide funding to DPOs to build their own skills and then engage with public bodies to ensure compliance

**Raise awareness**

* Increase training across all types of public sector staff

**Effective enforcement plan and monitoring system**

* Introduce Disability Impact Assessments
* Involve DPOs in policy making
* Use mainstream complaints processes
* Implement employment quota targets in the public sector

**Changing attitudes**

* Re-frame the Duty to consider the social model of disability

**Access**

* Ensure equal access to all sorts of public services
* Improve navigation and signposting to services, especially for parents of disabled children

**Support services**

* Assess disability/conditions quicker
* Provide particular support for more vulnerable groups
* Fund advocacy services
* Protect staff who need reasonable accommodation requirements from discrimination
* Acknowledge the negative impact of the lack of appropriate support services.

## Optional Protocol to the UN CRPD

**What is the Optional Protocol?**

The Optional Protocol to the UN CRPD allows individuals or groups of individuals to take a complaint to the UN CRPD Committee when one or more of their rights has been violated.

**Key point:** We asked about the Optional Protocol to identify priority areas for change.

Ireland has not signed the Optional Protocol and people are currently unable to make a complaint if their rights are violated.

Participants identified the complaints they would raise if the Irish Government signed the Optional Protocol. We have used this question to identify areas of priority action as discussed in Chapter 2. They include:

* Implementation of the social model of disability
* Consultation with DPOs
* Access to public services
* Failure to address discrimination and structural barriers in education, employment and training
* Institutional and bureaucratic barriers in diagnostic services and assessment of need process
* Access to legal aid and mechanisms to challenge discrimination
* Need for reform of legislation

## Government action in realising rights

**Key point:** There are actions that Government can take within 12 months, which would have significant effects on disabled people’s lives .

Participants were asked what actions the Government could take in the next 12 months.

Some of the most common actions were:

* Remove bureaucratic barriers on access to disability payments and funding
* Reform in line with disabled people’s voices
* Monitor the function of disability service providers and ensure their accountability
* Financially support and recognise the DPO’s role and ensure their representation in decision making
* Remove barriers to access support services and information
* Provide reasonable accommodations in the workplace and education
* Train staff in equality and inclusion and raise awareness among professionals and general public.

## Legislation and its effectiveness

**Key point**: There is a need for effective and genuine engagement with disabled people.

Legislative change is needed to address poverty, exclusion from decision-making, and reflect the social model of disability.

To advance full realisation of people’s rights, participants suggested the following changes in legislation and policy:

**Legislation**

* The Disability Act 2005 should reflect the social model of disability along with ensuring full compliance and enforcement.
* The Equal Status Acts 2000-2018 should ensure full accessibility to challenge discrimination.
* Repeal the Mental Health Act 2001
* Reform the Education of Persons with Special Educational Needs (EPSEN) Act 2004
* Remove discriminatory provisions around advance

healthcare directives from the Assisted Decision Making

(Capacity) Act 2015.

**Policy**

* Provide full access to Free Legal Aid
* Introduce a universal basic income for all disabled people
* Apply the self-assessment model from Revenue in all application processes for disability services and supports.

## The UN CRPD and statutory bodies

The DPO Coalition Steering Committee discussed the impact of UN CRPD ratification on the:

* Role of the National Disability Authority (NDA)
* The effectiveness of equality legislation and oversight bodies and processes.

Issues identified include:

**Role of the NDA**

The NDA need to:

* Engage effectively with disabled people in decision-making
* Use the social model in their work and reflect disabled people’s experience
* Review how they consult with DPOs

**Equality legislation and oversight bodies and processes**

* The State must ensure the definition of disability is consistent across all laws, regulations and statutory instruments.
* The review of the Equal Status Acts should address the role of Irish Human Rights and Equality Commission and the Workplace Relations Commission. And it should review how Deaf people are excluded when considering language barriers.
* The Workplace Relations Commission (WRC), as the key complaints process on discrimination, needs to be reviewed in terms of its accessibility and role.

This report was funded by the Department of Children, Equality, Disability, Integration and Youth.

This project was supported under the Irish Human Rights Equality Commission Grant Scheme.