

The role of Disabled Persons' Organisations (DPOs) in Ireland

DPO Network Position Paper No. 1

Plain English Version December 2023

Contents

Part 1	Introduction	1
1.1.	Who we are	3
1.2.	What is the UN CRPD?	3
1.3.	What does the UN CRPD say about the meaningful participation of DPOs?	4
Part 2	Key Messages	6
2.1.	Current characteristics of DPOs	6
2.2.	Co-Creation	7
Part 3	Understanding DPOs	8
3.1.	Origin and understanding of DPOs	8
3.2.	Membership	9
3.3.	What do DPOs do?	11
3.4.	Recommended characteristics of DPOs checklist	12
3.5.	What does meaningful participation look like?	13
3.6.	Key considerations for meaningful participation	16
Part 4	What DPOs need from the State: Recommendations	
	from the DPO Network	
Glossa	ry	19
Resour	rces	

Page

Part 1 Introduction

This paper sets out the DPO Network's understanding of the role of Disabled Persons' Organisations (DPOs) in advancing the effective and meaningful participation and inclusion of disabled people in Ireland. We explain what we mean by 'meaningful participation' on page four of this paper.

The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) recognises disabled people as having rights on an equal basis with others. This emphasises their right to fully and effectively take part and be included in society.¹

The UN CRPD further recognises DPOs as having the mandate (authority) to represent disabled people in issues concerning them. Article 4.3 of the UN CRPD, requires States to closely consult and actively involve DPOs in the decision-making process.

The DPO Network acknowledges the vital role and responsibilities of DPOs in representing and advocating for the rights and interests of disabled people as well as how they contribute to putting the UN CRPD into practice.

This paper aims to:

- share the views of the DPO Network about the role of DPOs in Ireland; and
- raise awareness and understanding of the role of DPOs in Ireland.

It is informed by the Committee on the Rights of Persons with Disabilities General Comment 7 (GC 7 see glossary on page 20). This sets out how disabled people should be involved in bringing about and overseeing the UN CRPD.

Part 2 of this paper outlines a number of key messages in supporting the bringing about of the UN CRPD.

The paper continues in Part 3 with:

- a definition of DPOs;
- a list of current types of DPOs and their functions;
- the essential characteristics of DPOs in line with international best practice;
- an exploration of the importance of these characteristics in promoting effective and meaningful participation. This includes seven Irish case studies to show how aspects of characteristics work.

Part 4 is the final part of our paper. We make recommendations to ensure that engagement with DPOs becomes a core element of State action when implementing the UN CRPD in Ireland.

The paper also provides guidance to members of the DPO Network, local, regional and national DPOs, civil society organisations and the State.

¹ General Assembly (2007). Convention on the Rights of Persons with Disabilities, A/RES/61/106.

Specialist words and descriptions explained

In this paper, we have described our views and recommendations with great care. There are some specialist words and descriptions that have specific meanings. If you come across a word or piece of legislation you don't know, you will likely find an explanation for it in our glossary on page 19.

1.1. Who we are

The DPO Network is an alliance of five national Disabled Persons' Organisations in Ireland. We work together to help ensure that the UN CRPD in Ireland is fully implemented.

The five DPO member organisations are:

- As I Am Ireland's National Autism Advocacy Organisation https://asiam.ie/
- Disabled Women Ireland (DWI) <u>https://www.disabledwomenireland.org/</u>
- Independent Living Movement Ireland (ILMI) <u>https://ilmi.ie/</u>
- Irish Deaf Society (IDS) <u>https://www.irishdeafsociety.ie/</u>
- National Platform of Self Advocates http://thenationalplatform.ie/

The DPO Network relies on disabled people's lived experience, expertise and analysis. We are led and informed by the active input of disabled people. Their input provides a unique opportunity for an analysis of the issues faced by disabled people that truly covers all areas of society.

The DPO Network is committed to the human rights and social model of disability. This model says that the exclusion, inequality, and discrimination that disabled people experience is not because of a person's disability but due to economic, cultural, social, and political barriers that continue in society.

1.2. 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 purpose of the Convention is to promote, defend and reinforce the human rights of all disabled people. This is the first human rights treaty to include representatives of disabled people, through DPOs, in putting into practice and overseeing the treaty in partnership with the State.

The Irish State ratified (signed) the UN CRPD in 2018. This means that the Irish State has committed to promoting and protecting the rights of disabled people in Ireland.

The UN CRPD recognises disabled people as active and equal partners in State action around disability.

The Convention sets out how disabled people must be able to fully take part in society on an equal basis with others. Taking part in society also includes other specific rights, such as the right to take part in political and public life.

1.3. What does the UN CRPD say about the meaningful participation of DPOs?

The UN CRPD acknowledges the importance of organisations of disabled people as representative organisations in advancing effective and meaningful participation.

What does meaningful participation mean?

Meaningful participation is where disabled people and DPOs have effective and active input in decision-making processes on a regular basis. It acknowledges, respects, values and considers the unique role and viewpoint of DPOs as organisations representing the diversity of disabled people.

Meaningful participation is an ongoing process, based on partnership with the State and state bodies. It requires listening to and discussing concerns identified by DPOs, and being willing to act upon them.

Meaningful participation requires the State to be open and to communicate outcomes of consultations to DPOs in a timely manner.

You can read about meaningful participation in practice on page 13 of this paper.

What the law says

The Committee on the Rights of Persons with Disabilities in GC 7 clarifies State parties' requirements under Article 4.3 of the UN CRPD. This Article requires State parties, first to consult closely and ensure the active involvement of disabled people and their DPOs on any matters which affect them.²

"... States parties should give particular importance to the views of persons with disabilities, through their representative organizations, support the capacity and empowerment of such organizations and ensure that priority is given to ascertaining their views in decision-making processes." Para 13, GC 7

GC 7 clearly establishes DPOs as representative organisations through which disabled people can engage with policy makers to represent and express the viewpoints of disabled people.

"In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, State parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations" CRPD Article 4.3

Article 33 of GC 7 guides States in effectively making sure DPOs take part in the overseeing and putting into practice the UN CRPD.

"Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process". CPRD Article 33.3

² General Comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention. Adopted on 9 November 2018. UN Doc CRPD. C/GC/7.

The UN CRPD, through articles 4 and 33, ensures the principle of 'nothing about us without us'.

Meaningful participation is not just an outcome in itself, but also a process.

As an outcome, it demonstrates how the human rights of disabled people are achieved in all areas of life.

As a process – through engagement, consultation and recognition – it directly contributes to achieving this outcome.

See Part 3 for seven case studies of how the active involvement of DPOs translates into meaningful participation.

Part 2 Key Messages

2.1. Current characteristics of DPOs

Self-representative: DPOs are self-representative organisations in which disabled people make up a clear majority at all decision-making levels of the organisation. DPOs promote, pursue and/or defend the equal rights of disabled people in all aspects of life of political, community, economic and cultural life in line with the UN CRPD.

Led and directed by disabled people: The Committee on the Rights of Persons with Disabilities has stressed that DPOs must be led, directed and governed by disabled people.

The voice of disabled people: The State is required to recognise the representative role of DPOs as the voice of disabled people in engagement and consultation processes, in accordance with GC 7. In addition, the Committee on the Rights of Persons with Disabilities has clarified that States shall give priority to the views of DPOs on any issues related to disabled people.

Strategic role: DPOs play a strategic role in overseeing how the UN CRPD is put into practice. To do this, DPOs require adequate and ongoing multi-annual core funding and resources. The State needs to fund, support and nurture emerging DPOs in Ireland.

Focus on promoting the rights of disabled people: DPOs can vary in their roles and functions. However, they all have an overarching focus on promoting the rights of disabled people. The work of DPOs is based on a stated commitment to the human rights and social models of disability and the UN CRPD.

Strength: Strong DPOs are essential to empower disabled people, including children and other groups who are underrepresented, who are additionally marginalised and who experience multiple forms of discrimination.

Structure: DPOs must have stated goals, rules, a membership base, clear decision-making structures and values aligned to the UN CRPD. DPOs are responsible for bringing their collective lived experience, expertise and analysis to policy spaces and are accountable to their members.

Independent collective spaces: DPOs are independent, collective spaces for disabled people to bring about social and systemic change. They are different from disability service providers and charities that provide services to disabled people. DPOs cannot be sub-groups of service provider or civil society organisations.

Supports for members: DPOs can offer supports to its members. Doing so makes it easier for its members to live independent lives or to uphold their rights in a measurable and meaningful way that can be measured.

Part of civil society: DPOs are part of civil society but different from civil society organisations (CSOs). CSOs do not meet the UN CRPD Committee's definition for DPOs.

Partnerships: Some DPOs, in particular, the national DPOs, are committed to working in partnership with the State, state bodies and civil society organisations (CSOs) in the cocreation of policies and practices that support the setting up of an inclusive society. This direct engagement of DPOs in policy spaces is a new and emerging process and reflects the commitment of DPOs to working with State parties to bring about social change.

2.2. Co-Creation

Co-creation is an inclusive and collaborative process that is about creating solutions with people, not for them. This is where disabled people and other stakeholders take part in the design, putting into practice and assessment of products, services, policies and systems. The aim of co-creation is to improve their efficiency and effectiveness, and to ensure the satisfaction of those who take part in the process. ('SISCODE' 2019)³.

Key features of co-creation include:

- the active involvement of disabled people and other stakeholders in exploring and identifying any problems or needs;
- the active involvement of disabled people and other stakeholders in creating, using and assessing solutions;
- a clear focus on stakeholders' experience;
- direct interaction with stakeholders; and
- the creation of platforms that promote continual dialogue among stakeholders.

³ <u>https://siscodeproject.eu/</u>

Part 3 Understanding DPOs

3.1. Origin and understanding of DPOs

How DPOs came about

Disabled Persons' Organisations (DPOs) came about:

- in response to the barriers in society that prevent disabled people taking part on an equal basis with everyone else; and
- as a reaction against the control of disabled people by others.

Definitions

The term, Disabled Persons' Organisation (DPO) covers a variety of organisations, made up of or primarily governed by disabled people. There is no universally accepted definition of DPOs.

The UN CRPD itself does not define fully what a DPO is. It does, however, give special recognition to organisations that represent disabled people by requiring the State and state bodies to engage with them. As stated in Section 1.3, article 4.3 of the CRPD recognises the role of DPOs as having the authority to engage with government on the issues that concern disabled people.

The CRPD Committee provides additional information, defining DPOs as:

'those comprising a majority of persons with disabilities – at least half their membership – and governed, led and directed by persons with disabilities.'⁴

DPOs are distinct from civil society organisations, for example:

- charities;
- disability service providers;
- family advocacy groups;
- access and human rights groups within disability service providers; and
- organisations run and controlled by non-disabled people.

The DPO Network defines a DPO as:

An organisation that is governed, led and directed by disabled people and in which disabled people make up a clear majority at all decision-making levels of the organisation.

⁴ Committee on the Rights of Persons with Disabilities, Guidelines on the Participation of Disabled Persons Organisations and Civil Society Organisations in the work of the Committee, CRPD/C/11/2 (April 2014)

3.2. Membership

DPOs are organisations 'by', 'for' and 'of' disabled people. They promote the philosophy of "Nothing about us without us", the idea that disabled people know what is best for them and that no decisions should be developed without their full and direct participation.

DPOs may focus on:

- people with different conditions across disability;
- disabled people with one type of impairment; or
- a single focus population group (for example, the Deaf community).

They can be local, national or international in scope and diverse in how they operate as well as in their communities and memberships. This diversity is important to make sure that disabled people's views, collective lived experience, needs and issues are considered when policies and programmes are developed.

Note: DPOs do not need to have a legal status to consult and engage with disabled people.

There are different types of DPOs. We describe five types below:

- 1. Single-impairment DPOs
- 2. Population-specific DPOs
- 3. Cross-impairment DPOs
- 4. Intersectional DPOs
- 5. Umbrella DPOs

Let's look at each of these types in turn and provide examples for each.

1. **Single-impairment DPOs** represent individuals with a particular type of condition. For example, As I Am.

As I Am was set up in 2014 and is the national advocacy organisation for Ireland's autism community. The organisation works to create a society:

- where every autistic person is accepted 'As They Are' equal, valued and respected; and
- that is inclusive, accessible, accepting and positive for autistic people.

As I Am provides a range of supports informed by the community. They also provide training and accreditation programmes for businesses, community organisations and services to become autism-friendly.

2. **Population-specific DPOs** can be organised to represent a certain population group and their specific experience of disability. For example, Irish Deaf Society.

The Irish Deaf Society is the only national Deaf-led representative organisation of the Deaf, and it serves the interests and welfare of the Deaf community.

- It provides educational, personal and social services to Deaf adults and their families.
- It is a member of the World Federation of the Deaf and the European Union of the Deaf.
- It consults with national, regional and international Deaf organisations and representative bodies about issues in society that impact on Deaf people.
- 3. **Cross-impairment DPOs** represent the interests of people with a variety of impairments. Independent Living Movement Ireland (ILMI) is an example of a cross-impairment DPO.

Independent Living Movement Ireland (ILMI) was set up as a Centre for Independent Living in 1992. It is a is a national representative organisation that promotes the philosophy of independent living and works to build an inclusive society. It believes that disable people should be able to directly influence policy decisions that impact on their lives. ILMI seeks to:

- remove barriers in society that prevent disabled people from fully taking part in society;
- challenge the denial of people's rights; and
- promote independent living.
- 4. Intersectional DPOs represent groups of people who experience multiple forms of inequality and disadvantage. An example of an intersectional DPO is Disabled Women Ireland.

Disabled Women Ireland (DWI) is the only dedicated organisation advocating for the rights of self-identified women, girls and non-binary/genderqueer/gender non-confirming disabled people in Ireland. It is a cross-impairment organisation whose members have a diverse (different) range of impairments and intersecting identities. DWI believes the only way to achieve real change is to advocate from an intersectional feminist approach. Intersectional feminism recognises the many different ways women experience discrimination.

5. **Umbrella DPOs,** which represent networks or alliances of DPOs at a national, European and global level. Examples include the DPO Network, the European Network of Independent Living (ENIL) and the World Federation of the Deaf.

The European Network of Independent Living (ENIL) is a Europe-wide, cross-disability network of disabled people and their organisations. The ENIL:

• promotes the rights of disabled people to live independently in the community; and

• represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross-disability and self-determination.

The World Federation of the Deaf (WFD) is an international non-governmental organisation that represents Deaf people worldwide. WFD is a non-profit organisation that works for human rights and equal opportunities for Deaf people everywhere. It aims to:

- improve the status of national sign languages;
- improve access to information and services; and
- promote the setting-up of deaf organisations.

3.3. What do DPOs do?

The specific functions of DPOs can vary from group to group. However, the general roles of DPOs include the following:

- campaigning together for social change;
- capacity building and provision of technical guidance on disability inclusion;
- education and awareness-raising within society;
- collective empowerment of disabled people through the development of shared analysis and strategic policy work;
- facilitating access to information and in some cases offer membership support services;
- monitoring human rights/acting as a 'watchdog' on disabled people's rights;
- collaboration with other DPOs, civil society organisations and State bodies;
- partnership building;
- providing peer support to members;
- participation in policy analysis and development on a local, national and international level and in measuring its impact.
- representing and mobilising organisations of disabled people.

DPOs have the collective, shared **expertise of lived experience**. This gives them a unique viewpoint to speak on the needs and issues of disabled people. DPOs foster the **empowerment** of disabled people by making sure they take part in the decision-making processes that affect their lives. This can lead to **better quality of life outcomes**.

3.4. Recommended characteristics of DPOs checklist

The New Zealand DPO Coalition is a group of DPOs that work together to advocate for the rights of disabled people in New Zealand. It developed a checklist of the characteristics an organisation should have to qualify as a Disabled Persons' Organisation.⁵

These characteristics are based on the UN CRPD. The DPO Network adapted this checklist for Irish DPOs and recommends that organisations meet the following characteristics as a DPO.

	Recommended key DPO characteristics checklist	
1.	The organisation has a formal structure and focus. It must demonstrate it exists	
	as a group of individuals with a common purpose and rules.	
2.	The organisation upholds and promotes the philosophy that disabled people have	
	the right to take part collectively in decisions that impact on their lives.	
3.	The organisation's primary goal, objectives and operations reflect and support the	
	UN CRPD.	
4.	The organisation is open to all disabled people who meet its membership criteria.	
5.	The organisation must be led by a significant majority of disabled people who	
	meet its membership criteria, including the criteria to reflect disabled people's	
	interests and issues.	
6.	Only disabled people who meet the organisation's membership criteria may elect	
	and vote for its governing body.	
7.	A significant majority of the organisation's members are disabled and reflect its	
	community of interest.	
8.	The organisation demonstrates that it has authority to speak on behalf of its	
	members.	
9.	The organisation responds to and is driven by the collective voice of its disabled	
	members who reflect its community of interest.	
10.	The organisation has a variety of ways to ensure its members are informed of key	
	decisions at both a local and national level.	
11.	The organisation must operate independently of the State, state bodies and other	
	non-DPO organisations.	

⁵ DPO Attributes, A review of Disabled Persons Organisations (DPOs) and their participation in implementing and monitoring the UNCRPD National Disability Authority (NDA) November 2021

3.5. What does meaningful participation look like?

Below are seven case study examples of DPO engagement in decision-making processes that support effectively taking part and being included in Irish society.

Case Study 1: Sligo DPO in taking part in decision-making processes at local government level through Sligo Public Participation Network

Sligo DPO, a cross-impairment group in Co. Sligo is run by disabled people for disabled people. The group takes a human rights approach to social inclusion using the social model of disability. It aims to empower disabled through:

- advocacy;
- supports; and
- influencing local public policy to achieve greater access and inclusion in Co. Sligo.

Sligo DPO is an active member of the Sligo Public Participation Network (PPN). A PPN is a network that allows local authorities connect with community, voluntary, social inclusion and environmental organisations. The Sligo PPN is the main way in which Sligo County Council and other formal bodies engages with groups, like Sligo DPO, in giving people a greater say in local government decisions which affect their own communities. As part of its work in influencing local public policy, Sligo DPO has provided disability equality and rights training to local councillors and local authority staff.

Case Study 2: The DPO Network takes part in consultations on the development of policy

Members of the DPO Network took part in consultation events with the Housing Agency in the development of the National Housing Strategy for Disabled People 2022-2027. In particular, these consultation events focused on the inclusion of appropriate disability terminology in the strategy document. The vision of this strategy is to support disabled people to live independently with the appropriate choices and control over where, how and with whom they live, promoting their inclusion in the community. The participation of DPOs in the development of the strategy made sure that the voices of disabled people were heard and acted upon.

In addition, the DPO Network is engaging with the Housing Agency to develop an Information and Communications Strategy as part of the National Housing Strategy for Disabled People 2022-2027 implementation plan.

Case Study 3: Independent Living Movement Ireland (ILMI) collective empowerment of disabled people through capacity building to inform local and national policy structures

DPOs, when resourced, can bring disabled people together to discuss issues and possible solutions on how society needs to change and how disabled people can engage in actions, including policy structures, to bring about that change.

'Strategies for Change' was an online activism programme developed by ILMI and funded by Rethink Ireland. Emerging disabled activists collaborated to develop collective learning to help build a new, inclusive Ireland where disabled people can fully take part as equals.

Case Study 4: Engagement of the National Platform of Self Advocates in the work of the Disability Matters Oireachtas Committee

The National Platform of Self Advocates is an independent national organisation run by people with an intellectual disability for people with an intellectual disability. The organisation was set up to make sure that the voices of people with intellectual disability are heard at all levels of public decision-making.

The National Platform of Self Advocates is regularly invited to participate in the Disability Matters Oireachtas Committee meetings to speak on subjects of interest to their membership.

At Oireachtas Committee meetings, all questions are asked at the same time and members use jargon and acronyms, which can make the meeting inaccessible to self advocates. The National Platform of Self Advocates put together a guidelines document to demonstrate how to run an accessible meeting. This is shared with the Disability Oireachtas Committee each time the National Platform attends a meeting. Accessible meetings benefit everybody.

Case Study 5: Independent Living Movement Ireland (ILMI) resourcing collective policy making with disabled people on the development of Personal Assistance Services (PAS)

ILMI created spaces (in person and online) to bring disabled people together to discuss Personal Assistance Services (PAS). This allowed disabled people to explore the challenges they experience. It also gave them the time and space to reflect on how an ideal PAS should function. Paid policy workers helped to facilitate these spaces. They were able to bring the policy context and framework to the discussions with disabled people. This allowed disabled people to design a collective approach to policy and decision-making that was strategic and would meet the needs of all disabled people seeking a PAS.

Having the time to build collective capacity like this was crucial for the DPO. This approach makes sure that any policy submissions or discussions with policymakers would be based on the collective views of disabled people.

Case Study 6: Irish Deaf Society building the capacity of state bodies on Irish Sign Language

The Irish Deaf Society (IDS) has a long relationship with the Citizens Information Board (CIB). An example of a collaborative project is a series of videos about 'Deaf Awareness Training' developed by the Citizens Information Board (CIB) in collaboration with IDS. CIB's aim in producing these videos was to make sure their staff had a sufficient level of Deaf Awareness. They also decided to publish the series on their website to make sure that the information is available to anyone who wants to learn more about the Deaf community. Awareness of the Deaf community is needed at all levels of public service to reduce barriers and highlight the experience and the issues Deaf people face daily.

The project demonstrates CIB's understanding of the importance and value of Deaf Awareness Training. The process also led to a deeper understanding of:

- how English is translated to Irish Sign Language (ISL);
- the costs involved;
- how changes to content involve re-shooting and editing of video content; and
- how the structure of ISL is very different to English: translation is not direct and involves adaption of English content.

Case Study 7: Participation of Disabled Women Ireland in the UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) reporting process

Disabled Women Ireland (DWI) recently made a submission to the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). CEDAW, like the UN CRPD is one of the United Nations Human Rights Conventions. DWI's submission was about a List of Issues that the CEDAW Committee will put to the Irish State on the situation of women in Ireland.

DWI asked that questions be asked on the following areas affecting disabled women's lives:

- 1. disabled women's access to healthcare;
- 2. gender-based violence and the experience of disabled women; and
- 3. disabled women's financial independence.

DWI identified these areas in consultation with DWI members and following desk-based research.

Ireland has obligations to disabled women under both the UN CEDAW and the UN CRPD. Despite these, disabled women continue to face discrimination and barriers to fully taking part in society as a result of intersecting identities - both as disabled people and as women.

DWI took the opportunity to contribute to the development of the List of Issues. It saw it as a way of holding the State to account on the issues affecting disabled women. This is the first step in the treaty reporting process. At a later date DWI will contribute further by developing a shadow report to the CEDAW Committee ahead of the State report.

3.6. Key considerations for meaningful participation

DPOs require essential supports from the State and state bodies to realise their meaningful participation. These essential supports or pre-conditions include:

- **Recognition of DPO's right to be partners**: DPOs have a right to be partners in decision-making and consultation processes, in accordance with the UN CRPD.
- Engagement of DPOs as partners in the planning, design and implementation of consultation processes: Consultation should be based on openness, mutual respect and meaningful dialogue set with reasonable and realistic timelines.
- **Empowerment and capacity building of DPOs**: This will enable DPOs to effectively engage with the State and state bodies including on the development of technical, administrative and communication skills.
- **Provision of reasonable accommodation**: This should include personal assistance services (PAS) and information in accessible formats such as Irish Sign Language interpretation, screen reader assistive technology, Easy to Read and plain English.
- Accessibility: All facilities and procedures related to decision-making and consultation processes should be accessible.
- Allocation of funds: Funds should be provided for disability-related costs to DPOs to attend meetings and take part in decision-making and consultation processes.
- **Funding of DPOs**: DPOs should be given multi-annual funding so they can fulfil their functions. This will allow DPOs the time and space to grow and support the collective capacity of their membership to engage and actively take part in key policy discussions.
- **Consultations with DPOs**: Consultations with DPOs should genuinely represent collectives of disabled persons in all their diversities including women, children and other individuals who experience multiple forms of discrimination.
- **Reviews**: There should be periodic reviews of how effective existing ways of taking part and consulting operate.

Part 4 What DPOs need from the State: Recommendations from the DPO Network

"States parties should strengthen the capacity of organizations of persons with disabilities to participate in all phases of policymaking, by providing capacity-building and training on the human rights model of disability, including through independent funding. States parties should also support persons with disabilities and their representative organizations in the development of the competencies, knowledge and skills required to independently advocate for their full and effective participation in society..." Para 60, General Comment

- 1. Agree criteria for DPO recognition and support DPOs to meet these criteria. Currently, there is no national organisation or Government department assigned to determine whether an organisation qualifies as a DPO, in line with the definition of a DPO set out by the Committee on the Rights of Persons with Disabilities in GC 7. The DPO Network recommends that the State adopts the suggested checklist included in this position paper on page 12.
- 2. Establish and maintain a national register of DPOs.

There must be a national register of DPOs. The DPO Network recommends that the National Disability Authority (NDA), as the independent statutory body that provides evidence-based advice and research to Government on disability policy and practice, develop and maintain such a register.

3. Ensure DPOs have adequate, multi-annual core funding to effectively take part in and oversee and put into practice the UN CRPD. Having access to adequate core funding and resources to support their operations,

Having access to adequate core funding and resources to support their operations, organisational development and advocacy priorities will enable DPOs perform their role(s) with independence and adequate capacity.

4. Support DPO technical and organisational capacity development.

Such support will allow DPOs to acquire skills and to meaningfully engage in local level and national policy development and monitoring. This should include targeted support to foster representation of the most marginalised and underrepresented groups of disabled people.

5. Develop comprehensive strategies and mechanisms to make sure that disabled children, young people and women and other underrepresented groups can take part in consultations, decision-making processes and policy development that affect their lives.

For instance, by strengthening, supporting leadership and developing the voices of young people, women and other marginalized groups of disabled people. This will make sure that under-represented groups who face intersectional discrimination are included. Paying particular attention to underrepresented groups of disabled people is important. Some groups may be excluded from consultations or participation in decision-making because they lack access to information and opportunities.

Glossary

The following is a list of word, terms and descriptions used in this paper.

Advocacy This is about supporting people to speak up and get involved when decisions are being made about their lives.

Article 4.3 of the UN CRPD This is a requirement of the UN CRPD (UN CRPD is explained below). It states that State parties shall consult and actively involve disabled people when they are developing and putting in place laws and policies for the UN CRPD. This includes consulting and involving children through their representative organisations.

Co-creation An inclusive process where those involved work together to design, implement and assess products, services, policies and systems. The aim is to improve the efficiency and effectiveness of these products, services, policies and systems.

Disabled Person's Organisations (DPOs) DPOs are organisations that are led, directed and governed by disabled people for disabled people. These organisations are committed to the social model of disability (see later in glossary). They also promote and advance the human rights of disabled people in line with the UN CRPD. DPOs are also known as Organisations of Persons with Disabilities (OPDs).

Disability Service Provider An organisation that provides services to disabled people. Such services are also usually delivered on a contractual basis with funding from the State.

General Comment 7 of the UN CRPD A document by the Committee on the Rights of Persons with Disabilities. This document explains how disabled people should be involved when bringing about and overseeing the implementation of the UN CRPD (see below).

Human Rights Model of Disability This model recognises that disability is a natural part of human diversity (difference); that disabled people are entitled to enjoy the same rights as everyone else in society; and that disabled people's rights need to be promoted so they can fully take part in society.

Intersectionality A framework for understanding how class, disability, gender, race and other systems of oppression 'intersect' (cross paths) with one another to create different kinds of discrimination and exclusion for groups experiencing discrimination in many different ways.

National Disability Authority (NDA) The independent statutory body that gives information and advises Government on policy and practice relevant to the lives of disabled people.

Social Model of Disability A way of understanding disability which says that the exclusion, inequality and discrimination experienced by disabled people are not caused by a person's condition but are due to economic, cultural, social and political barriers in society.

UN CEDAW The United Nations Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) is a human rights treaty against the discrimination faced by women across the world. The aim of this treaty is to fulfil, protect and respect women's human rights. The Irish Government ratified (signed) the UN CEDAW in 1985.

UN CRPD Committee on the Rights of Persons with Disabilities This is a group of 18 democratically elected independent experts who check how well governments are bringing about the UN CRPD.

UN CRPD The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) is a human rights treaty which sets out how disabled people must be able to fully take part in society on an equal basis with others. The Irish Government ratified (signed) the UN CRPD in 2018. In ratifying the UN CRPD, the Irish Government is committed to promoting and protecting the rights of disabled people in Ireland.

Resources

General Assembly (2007). Convention on the Rights of Persons with Disabilities, A/RES/61/106. <u>https://www.un.org/development/desa/disabilities/resources/general-</u> <u>assembly/convention-on-the-rights-of-persons-with-disabilities-ares61106.html</u>

Committee on the Rights of Persons with Disabilities, General Comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention <u>General comment No.7 on Article 4.3 and 33.3 - the participation of persons with disabilities in the implementation and monitoring of the Convention | OHCHR</u>

A review of Disabled Persons Organisations (DPOs) and their participation in implementing and monitoring the UNCRPD, National Disability Authority (NDA), November 2021 <u>A review of Disabled Persons Organisations (DPOs) and their participation in implementing</u> and monitoring the UNCRPD Nov21 (nda.ie)

Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making, National Disability Authority, September 2022

Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making - National Disability Authority (nda.ie)



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This project is supported by the Department of Children, Equality, Disability, Integration and Youth



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