

The Disabled Person's Organisation (DPO) Network

Opening Statement to the Joint Oireachtas Committee on Disability Matters

24th November 2022

Dear Chairperson, Deputies and Senators, the DPO Network welcomes the opportunity to be here today. The DPO Network is an alliance of Disabled People and their organisations (five DPOs) in Ireland who have joined together as we have a common interest in the implementation of the UN Convention on the Rights of Persons with Disabilities in Ireland.

The five DPO member organisations of the DPO Network are:

- 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

The DPO Network is committed to the human rights and social model of disability which says that the exclusion, inequality, and discrimination disabled people experience is not the consequence of our impairments but a result of the economic, cultural, social, and political barriers which persist in society.

All our work is led and informed by the active participation of disabled people based on their lived experience. Given the broad membership base of the members of the network, the Network gives a unique space for a genuinely cross-impairment analysis of the issues faced by disabled people and provides a space for networking between the organisations.

DPOs and the Social Model of Disability

DPOs work from an explicitly human rights and equality approach to build a more inclusive society. We are informed by the social model of disability

and therefore, in all our documentation and our discussions we always use the term “disabled people” to reflect the values of equality and empowerment which are at the core of the DPO Network.

The role of DPOs includes working with policy makers, legislators, and Statutory bodies to develop policies and campaigns based on disabled people’s lived experiences and to remove barriers that restrict life choices for disabled people. When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives. Barriers are not just physical. Attitudes found in society, based on prejudice or stereotypes (also called disablism) or outdated ideas or perceptions around disability, also disable people from having equal opportunities to be part of society. Disabled people developed the social model of disability because the traditional medical model did not explain their personal experience of disability or help to develop more inclusive ways of living.

DPOs are civil society organisations **of** disabled people as distinct from disability service providers (DSPs) and charities **for** 'clients' and 'service-users'. Disability service providers, most of whom are funded at least in part by the State, are also resourced by boards and staff who are mainly non-disabled people.

The DPO Network recognises that this Committee and other State agencies are beginning to recognise the primacy of DPOs as per Article 4.3 and General Comment 7 of the UNCRPD. This recognition of the role of DPOs in the development of policy and direct consultation is welcomed.

However, the DPO Network is concerned that with the increased awareness of the role of DPOs without a real plan for how our development is to be supported, we will either be unable to participate in the representative and consultative spaces or that calls for DPO involvement could result in tokenistic participation.

On that basis, the DPO Network would like to raise the following observations in how DPOs should be resourced locally and nationally to inform the development of policies to implement the UNCRPD.

The need to invest in the development of Disabled Persons Organisations

To speak about the participation of DPOs in local structures such as Public Participation Networks, we first must recognise that there has been an historic lack of investment to build collective rights-based spaces for disabled people in Ireland.

Due to the dominance of disability service providers and the disability industry in Ireland, disabled people and DPOs have not directly benefited from any investment in community development, social inclusion, or collective approaches. This has had a serious impact in disabled people's voices being heard in policy, Local Area Coordination, PPN's and community development locally and nationally. Hopefully with the increased recognition of the primary role of DPOs in the UNCRPD we will see a systemic shift towards investment in DPOs to organise collectively to bring about a more inclusive society.

A mechanism of DPO prioritisation needs to be concretely identified and put in place. As the DPCN has itself highlighted, a consultative body or forum without this mechanism cannot fulfil the consultation requirements of the CRPD.

A method of identifying bona fide DPOs needs to be established in partnership with existing DPOs. (One example of this is the checklist developed by the DPO Coalition of New Zealand).

The criteria required to be recognised as a DPO need to be available and accessible to groups representing disabled people, and support needs to be available to enable appropriate groups to meet any criteria additional to those outlined under General Comment 7. (For example, should it be necessary for an organisation to have a Terms of Reference or Constitution, or to register with a body such as the CRO to secure

recognition as a DPO - advice and practical support should be available for this.) Disabled people have, as a community, significantly decreased access to financial and educational resources and many DPOs and local disabled people's groups are run on an entirely voluntary basis - navigating criteria such as these may fall outside their skillset without support to build these skills being made available.

While it is important to have a rigorous and transparent method of identifying DPOs and distinguishing them from all other types of organisations, it is important that all genuinely self-representative groups advocating on behalf of their membership are adequately supported to do so. We have a relatively sparse and new DPO landscape in Ireland, and investment in empowering this sector to grow is imperative to advancing the CRPD on both a local and national level.

PPNs

Currently PPNs require that an organisation must either operate solely within a Local Authority area, or that it has a specific local branch representing the area, distinct from its national organisation, to participate. Not only does this not reflect the ways in which many DPOs are organised - due, in part, to insufficient resources to set up distinct local branches at a county level - but information on what constitutes a local branch is difficult to obtain.

PPNs have, to-date, not been set up or developed with enabling the equal participation of disabled people as a goal. Before PPNs could be considered as appropriate fora for DPO consultation they must (in addition to adopting the distinction mechanism mentioned above) be reviewed to ensure that their processes and meetings (including remote access options and physical locations) are fully accessible to **all** disabled people who wish to participate in them. This is likely to entail redesigning aspects of their current operating methods and ways of distributing information relating to the PPNs work, and this review needs to be carried out in partnership with DPOs and local disabled people.

Implementation of the UNCRPD will require the full and active participation of disabled people in the design, implementation, monitoring and evaluation of policies to promote effective social inclusion. The UNCRPD is not solely about policies and frameworks in relation to disabled people's lives, it is ultimately about ensuring that disabled people and their needs are given due regard in ALL aspects of public, cultural, economic, civic, and political life in Ireland.

Lack of access to community supports (in line with UNCRPD) if living in congregated setting or in the community

In addition to the lack of services and under-provision of existing resources, community support services are still delivered on a diagnosis-basis which is overly burdensome to navigate and excludes a significant proportion of disabled people who need support to live a full life in their communities.

Amongst other essential community supports it is time for a needs based Personal Assistance Service (PAS) to be established on a national statutory basis. We also need access to Augmentative and Alternative Communication (AAC) supports (incl. ISL, Braille & AAC for non-speakers) to be made available to disabled people irrespective of where they live.

Local Area Coordination and Community Development

The core principles of Community Development (Empowerment, Collective Action, Participation, Equality and Social Justice) reflect the values of the work of DPOs. There is a real need for community development approaches and supports to be directed towards the development of DPOs locally and nationally.

With appropriate resources, we could employ staff to build our collective capacity. We could set up processes and systems to encourage the participation of disabled people in collective strategic thinking. We should be supported to seek our places as DPOs in social inclusion structures and to nominate our representatives not only to bring our issues to the table but have the discussions brought back to our organisations. It would allow

us to move away from an individual bringing their own lived experience to the table and allow us to work on the issues that affect us all.

Appropriate investment in DPOs would also resource the participation of disabled people in local and national forums. In many spaces the only people sitting who are tasked with attending meetings in a non-paid capacity are disabled people, who are meant to give their time and expertise for free. With investment in DPOs, we can either employ staff or resource and support volunteers to bring the collective authentic voice.

Disability Equality Training for Statutory Bodies

DPOs tend to talk about Disability Equality training. This is training that is based on the social model of disability and is based on equality and human rights for disabled people. It aims to inform policy and practices and embed approaches to ensure the active participation of disabled people in society. From the DPO Network perspective, Disability Equality is delivered by a disabled person with the professional and lived experiences on a paid capacity. Ideally it is a disabled activist who is actively involved in a DPO which can provide follow-on support to a Statutory Body.

Investing in DPOs to ensure implementation of the UNCRPD

Ireland's obligations under the UNCRPD are to ensure that State invests in policies, practices, and supports to include disabled people in society as equals. Central to the effective implementation of the UNCRPD in Ireland will be the full and effective participation of disabled people in the design, delivering and monitoring of policy at a local, regional, national level.

The CRPD Committee have made clear that State parties have broad responsibilities relating to funding and building capacity of DPOs, including disabled women and children, to enable them to fulfil their consultative and monitoring roles in relation to the Convention. This can only be done through strategic, multi-annual investment in DPOs. This will allow us to create spaces for disabled people to work collectively together: to identify what structures to engage in that maximise our time and effort; and to bring collective policies to influence structures such as

the PPNs. Investing in DPOs will also allow us to lead on consultation with disabled people and to nominate our representatives to bring our voice to the table.

The UNCRPD cannot be implemented locally, regionally, or nationally without investment. It is time to ensure disabled people are resourced to collectively have our voices heard. It is time for “Nothing About Us Without Us” to become a reality.

Thank you.