

## **The Disabled Person's Organisation (DPO) Network**

### **Opening Statement to the Joint Oireachtas Committee on Disability Matters**

16<sup>th</sup> February 2023

**Dear Chairperson, Deputies and Senators, the DPO Network welcomes the opportunity to be here today.** We are an alliance of Disabled People and their organisations<sup>1</sup> 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.

We are 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 DPO Network gives a unique space for a genuinely cross-impairment and inter-sectional analysis of the issues faced by disabled people and provides a space for networking between the organisations.

There are 3 topics for discussion today: Disability proofing, Data, and the Sustainable Development Goals. We will address each of these topics in turn.

#### **Disability Proofing and Data Collection**

Article 31 of UN CRPD, Statistics & Data Collection, calls on State Parties to the Convention to undertake to collect appropriate information,

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<sup>1</sup> The five DPO member organisations 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.

including statistical and research data, to enable them to formulate, implement and assess UN CRPD and to develop evidence-based policies. Among other quality controls it requires the results of any data collection to be provided in accessible formats for disabled people.

The responsibility for data collection and statistics lies with the State and the inclusion of DPOs in the collection, analyses and dissemination of data is in-keeping with the principles of CRPD.

Data collected must take into consideration the social model of disability. This requires a focus on the barriers in society that prevent disabled peoples' full participation in society on an equal basis.

Disabled people must be involved in all stages of data collection from planning to execution and analysis, including those who may be most marginalised. This requires additional planning, additional time and additional expense and we refer the committee to the NDA's published guidelines on meaningful engagement with disabled people on how to do this well.

The Human Rights Based Approach to Data proposed by the Office of the High Commissioner for Human Rights (OHCHR) is to ensure that the quality, relevance and use of data is consistent with international human rights norms.<sup>2</sup> The OHCHR recommends that this approach is incorporated into data collection and disaggregation by States to facilitate the implementation of the CRPD.

The Human Rights Based Approach focuses on key principles to guide data collection and disaggregation, namely:<sup>3</sup>

- Participation
- Data disaggregation
- Self-identification
- Transparency
- Privacy and accountability

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<sup>2</sup> <https://www.ohchr.org/EN/Issues/Indicators/Pages/documents.aspx>

<sup>3</sup> <https://bridgingthegap-project.eu/frequently-asked-questions-on-human-rights-indicators-of-the-crpd/>

Disability-data collection methods and tools are a matter of current technical debate and development. However, under Article 31, the CRPD Committee recommends the use of the Washington Group Short Set of Questions on Disability<sup>4</sup>, which has been designed for integration into national censuses and household surveys. This method has been widely tested by countries.

Its use is supported by the CRPD Committee, UN agencies and others to secure a baseline for comparison to measure the impact of the SDGs on persons with disabilities

The DPO Network would like to see this methodology applied in Ireland.

The view of our members is that there is not enough appropriate research currently available to provide the extensive evidence base that is required to develop successful policies and implementation of the UN CRPD.

In line with the NDA paper on their overview of Article 31 we call on Irish state bodies to expand their qualitative and quantitative data collection and research activities relating to human rights and how they impact on the daily lives of persons with disabilities.

Other areas of concern include:

Data needs to be collected applying a consistent model of disability rights. Currently a number of agencies and organisations collect data on issues relevant to disability using varying models, for example, based on medical, social or human rights.

Data collection and disaggregating in the area of disability should include information on gender, ethnic or racial origin, age and other potential characteristics that can lead to discrimination.

The Central Statistics Office (CSO) has a responsibility to collect meaningful data that can support the implementation of UN CRPD. Our members are keen and willing to engage with the CSO. Indeed, some members including the Irish Deaf Society have made submissions to suggest changes to questions and terminology that will address a lack of

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<sup>4</sup> <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-enhanced-wg-ss-enhanced/>

clarity in census data collection as relevant to culturally Deaf people in Ireland. The CSO have not responded as yet to our members submission. Disabled people must be able to maintain agency (control) over their personal data and be supported in accessing, securely sharing, understanding the use of and controlling and deleting their data.

## **Sustainable Development Goals**

The 2030 Agenda for Sustainable Development was adopted by all UN Member States, including Ireland, in 2015. At its heart are the 17 Sustainable Development Goals (or SDGs).

These goals are important for all of us as members of the human race who share this planet. Goals like No Poverty, Zero Hunger, Good Health and Wellbeing and Clean Water and Sanitation, Reduced Inequalities seek to ensure that the basic needs of all human beings of all nations are met. We should be able to assume that in a first-world country like Ireland, no-one would be left hungry, cold or without necessary medical treatment.

Sadly, we know from many studies, that one of the groups in Irish society with the highest rate and risk of poverty are those who are unable to work due to a lack of supports and reasonable accommodations. In the current cost of living crisis, we know that disabled people are disproportionately affected. No-one, disabled or non-disabled, should be afraid to turn on the heating, unable to buy food to eat, or left waiting on a hospital trolley for days.

Beyond those basic needs, many of the Sustainable Development Goals are about planning for a better future, a better society and a better world, with reduced inequality, sustainable communities and climate action. Sustainability is all about planning - disabled people are masters at planning, in every aspect of our lives, because we have to be, in a world which in so many respects has not been designed by or in consultation with us.

Sustainability in Ireland means organising our collective affairs in a way that ensures the ongoing wellbeing of all of us now and into the future.

**DPO Network Members:** 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. Chairperson – Jacqui Browne, [chairperson@dponetwork.ie](mailto:chairperson@dponetwork.ie). [www.dponetwork.ie](http://www.dponetwork.ie)

The DPO Network believe that the principles of sustainability must be brought to bear on planning disability services and supports for us now and for future generations of disabled people in Ireland. As the population grows so too will the numbers of disabled people – but where is the planning for the timely assessment of needs, early intervention, care supports and income supports for disabled people? And crucially, where is the plan for a Personal Assistance Service, accessible housing and transport schemes, among other supports that enable disabled people to achieve independence, access employment, and participate in this society as full and equal citizens and live lives of autonomy and dignity?

The SDGs are meant to guide us in creating the kind of world we all want to live in. To create it, we need to plan and that plan must take account of the needs of disabled people, and be created in collaboration with disabled people.

Currently, the Department of Communications, Climate Action and Environment leads Ireland’s implementation of the SDGs. It is essential that this Department works in collaboration with the Department of Children, Disability, Equality, Integration and Youth to create a disability-specific roadmap to ensure that disabled people are not forgotten about in the implementation of the SDGs. The DPO Network also urges that impact assessments are carried out on all SDG strategies which are likely to have an impact on disabled people, including, for example, those targeting the reduced use of fossil fuels - disabled people, through their representative organisations must be consulted in identifying the challenges, opportunities and priorities for these strategies.

Every human being who lives long enough will probably be disabled someday. So it’s in everyone’s interest that politicians like yourselves remember our needs when you’re making policies for all our futures.

Thank you.

Attendees representing the DPO Network today:

Jacqui Browne (Chair)

Grace Murphy

Amy Hassett

Nem Kearns