

Submission asking DPOs and self-advocates to make a submission on the UNCRPD and the reality of human rights for people with disabilities in Ireland with a specific focus on highlighting solutions and what is working in local areas.

Question: Are you a DPO or a Self-Advocate? Please provide as much detail as you can on why you are considered a DPO or Self Advocate (max 400 words).

I am a self-advocate. My experience in disability rights is from lived experience. I have a number of disabilities and impairments I was born with and a number I have acquired. My sight, hearing, mobility and balance are all affected.

I had to retire from work on medical grounds in 2009. I am in receipt of Invalidity Pension, have home help hours allocated and a number of other supports. I attend over 15 different health care professionals in over 8 separate hospitals and clinics. I am impaired in my sight, hearing, mobility

However, before I had to give up work I had worked for over 20 years in research, policy and information roles in NGO who advocated for adult literacy, women, interculturalism, employment rights, the rights of the unemployed and other areas of social justice.

I volunteer for the Special Olympics.

Question: What do you think is the role of DPOs, and self-advocacy is under the UNCRPD (max 400 words)

To work to remove the various barriers that may hinder disabled people from their full and effective participation in society on an equal basis with others.

To facilitate and provide training and other needed supports to disabled people for their effective participation and inclusion in society as self-advocates and as the voice representing disabled organisations

To facilitate and provide training and other needed supports to disabled people for their effective participation and inclusion in society as non-disability advocates. To ensure we are not pigeon holed as the voice of disability rights only and that are talents and skills and expertise are over looked.

Question: What do you think is important to be on the agenda for an event like this (max 400 words)

What is important **not to be on the agenda** is talk of visions and plans and time and any retrospective talking about past plans or programmes which have not been effective.

We also don't want to see a simple list of different groups or individuals talking. Especially when the larger groups aren't kept to a tight timeframe.

The focus must be as much on adults as children.

A possible agenda

Where do disabled people participate currently in Ireland?

Where are they seen? How are they seen and perceived?

What do disabled people want to change?

How do we change that?

How to get action, funding not words

Question: What ways are available to you to provide your feedback and participate in bringing about change in relation to human rights in your local area (max 400 words)

There are none in my immediate local area. There are in the capital city. I could join groups and get involved in a variety of actions if I can the money and support to do so and if my time wasn't taken up with just trying to stayed housed and other bare minimums.

However mainstream groups are generally not accessible. Building are not accessible, There is insufficient public transport. There has been a marked loss in the number of blue badge parking spaces available in the city centre. It is very difficult to actually get out there and get involved and then stay involved.

Social media is a key place for advocacy. Especially X aka formerly called Twitter.

Question: What are the key issues that you believe are affecting your human rights and having equal opportunities like everyone else in your local area (max 400 words)

The multiple structural inequalities and discrimination within measures that purport to support housing, health, transport, and education. From the small everyday ones to the huge policy issues structural inequality and ableism prevents me from playing a full part if society and having my voice heard. Some examples are given below. This are just a selection.

Social media does allow for some participation despite other barriers. However, it is hard to even take part in social media spaces if you don't have a good phone and other IT equipment that can support Assistive Technology. If you have never been shown how to use it and if there are no training courses or places to go to develop the confidence and skills needed. Not complete beginner courses. Too much training presumes disabled people have no confidents at all. But training to meet you where you are now and allow you to flourish as a self-advocate.

There also aren't enough central information places telling us about what grants and supports are out there through Vision Ireland etc. You sometimes fall over information by accident.

Housing

The Dublin City Council Housing Adaptation Grant where I am expected to pay for an architect before applying, an up-front expense which cannot be claimed back. I also can't claim the VAT costs back as my income is not high enough to be taxed. Yet VAT costs are excluded from the grant. These two facts impact me disproportionately as a disabled person as 1) my income is lower 2) I have no capacity to save due to the higher cost of living of disabled people. The grant is also capped at a level way below current costs of housing adaptations. Disabled people on bare minimum disability payments are expected to match 5% of the DCC grant.

The lack of suitable social housing that supports independent living.

Education

The absence of fully funded part time and flexible funding for under and post graduate opportunities.

Disabled people are excluded from post graduate education and research in particular. Even more so if they are low income. This in turn excludes disabled people from spaces they could have their voice heard and have the opportunity to take part in civil society.

The SFI, IRC, SUSI, DSP, FSD and every other funding source or programme exclude huge numbers of post graduate disabled students especially if they are low income or otherwise unable to subsidise and self-finance their studies. For example:

The IRC treats part time study as equivalent to full time in its funding criteria and restricts funding allowed to formerly part time applicants. This is disproportionately discriminatory against disabled students.

Part time PhD are expected to be completed in 6 years. Why is it not pro rata meaning the same amount of time? Why is extra time not afford to disabled researchers?

The Department of Social Protection have refused to build on the change in regulations brought about by groundbreaking Catherine's Law. Government has refused to widen access to other disability payments. The reasons given show a deeply ingrained ableism with the decision-making levels of the civil service and a lack of political will by the Government.

The absence of additional, individual research, travel, equipment and training budgets for disabled researchers to reflect the additional costs we incur.

Transport

Existing schemes are too narrowly defined excluding people with the same set of limitations and symptoms as some illness/disease are included and not others.

Long Term Illness Scheme similarly is based on illness not impact on life.

Question: What are the solutions that you believe would help make things better and that Government should be supporting (max 400 words)

Reduce the barriers facing disabled people. I can not fully participate in society and have my voice heard if I am constantly worried about my housing, my finances and my very status and standing in Irish society.

Scrap the Green Paper on Disability Reform in its entirety and start again with full consultation with DLO and grassroots activities.

Hold an enquiry into why and how the recommendations of the Citizens Assembly and Joint Oireachtas Committee on care were reduced with a particular emphasis on why the phrasing 'Family Care' was chosen to the exclusion of 'Home and Community'. Investigate why people at senior government level think that 'parents' and 'carers' are the same thing. Interrogate why ableist language was not only included but not recognised when pointed out.

This is a necessary exercise not only for Government, opposition and civil society accountability in the view of the referendum results. But also, to ensure that such biased and inherently ableist decisions are not made in the future.

Make education and training easy and attractive for disabled people at all levels.

Address all of the examples above and the very many that will have been identified in other submissions.

Provide more and wider funding to disabled led organisations

Provide more and wider funding to disability organisations on self-advocacy programmes

Make a fund available that self-advocates could avail of to buy phones, IT and other equipment.

Question: Would you like to be considered to attend this event in person or would you like to attend this event online? In person

Question: Would you like to speak at this event? Yes