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Neuro Pride Ireland

**Opening Statement to the Joint Oireachtas
Committee on Disability Matters
on the role of DPO's and self-advocacy in
providing equal opportunities under UNCRPD
implementation**

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A Cathaoirleach, a Leas-Chathaoirleach and esteemed Members of the Committee, thank you for your invitation to this Committee session today.

Neuro Pride Ireland is Ireland's only national cross-neurodivergency Disabled Persons Organisation, and we represent neurodivergent people from, or living on, the island of Ireland. We were founded as a cross-neurodivergency organisation in response to community need, as the majority of neurodivergent people have more than one neurodivergent identity; for example, up to 80% of autistic people also have ADHD.

As well as holding peer support and social groups for our approximately 1,000 members and an annual festival of social and cultural events, we produce educational materials, and actively advocate for neurodivergent people's right to full participation in all aspects of society.

Neuro Pride Ireland is a Disabled Person's Organisation as all members of the founding committee, organising committee and additional volunteers are neurodivergent, with most of us also having other physical impairments as such we appreciate the Committee's invitation to participate in this discussion today.

Neuro Pride Ireland firmly believes in the Disabled community maxim 'Nothing About Us Without Us' and believe that the voices of those with lived experience should be prioritised over those of service providers, charities and care givers, thankfully this belief is also outlined within the UNCRPD.

We recognise that the role of DPOs and self-advocates is to champion the views and lived experience of disabled people in order to inform policy and legislation which directly impacts disabled lives. But we also recognise the States' role to ensure disabled voices are heard throughout all decision stages that will impact disabled lives. To fail to do so is to fail to meet obligations under the cross-cutting Articles 4.3 and 33.3 of the convention and also a failure to meet general comment 7 which directly explores this principle.

But it isn't enough to provide us a space to share our thoughts, the State must ensure that the process is accessible to DPOs. This covers so much more than I could begin to touch on in 5 minutes so I will focus on capacity building.

To be able to fully engage in the ideal level of consultations, we believe the state first has to recognise that many DPOs are grassroots organisations relying on unpaid labour of disabled volunteers. As such the needs of each DPO will vary depending on the skills and availability of its team. For meaningful participation, the State must help in the capacity building of DPOs and remain flexible in its approach to this. For example capacity building for some DPOs may include computer literacy education but this is not a need for others. Like most things in the world of accessibility we cannot approach this with a one size fits all approach, but instead must be flexible and responsive to the needs of individual DPOs.

When considering this capacity building, we must also make allowances for DPOs as they develop their knowledge of the processes we are asked to engage with. For example, writing submissions can be intimidating, I was lucky to receive informal peer support from the amazing volunteers in Disabled Women Ireland, when I wrote my first submission. However

we cannot allow rigid bureaucracy standards to be a barrier to emerging or smaller DPOs from engaging with the State.

When discussing capacity building I feel its imperative to mention that a disabled person's ability to engage voluntarily should not be held against them when considering payments such as Disability Allowance. Most DPOs, if not all, are understanding of fluctuating capacity in a way that is not currently understood by the greater society. Take me for instance, I am here today, however that is due to the support of my family and the team in Neuro Pride Ireland. These occasional engagements are not indicative of mine or any other disabled persons ability to engage in full time or even part time employment. If this DPO engagement endangers a disabled person's income support, that within itself is a barrier.

While I am conscious of time I implore you to also consider

- The need for a registration of DPOs,
- The need for non directive core funding
- The need to keep the door open for small or emerging DPOs to join the conversation
- The need to compensate DPOs for our labour e.g. travel allowance, childcare allowance
- The need for accessible information and meetings

And I encourage you to consider the incredible work already done on how to provide meaningful participation for DPOs, in particular

- UNCRPD General Comment 7
- DPO Network Position Paper 1

Once again we wish to thank the Committee Members for this opportunity today, and look forward to engaging with you on this topic and answering any questions you may have, both today and in the future.

References

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 : Committee on the Rights of Persons with Disabilities

https://digitallibrary.un.org/record/3899396/files/CRPD_C_GC_7-EN.pdf

The role of Disabled Persons' Organisations (DPOs) in Ireland. DPO Network Position Paper No. 1 - November 2023

<https://irishdeafsoc.wenginepowered.com/wp-content/uploads/2023/12/The-Role-of-DPOs-in-Ireland-2023-Digital.pdf>

