

## **Disability Policy in Focus**

DPER Knowledge Sharing Symposia for Improved Policy Policymaking and Outcomes event

June 18<sup>th</sup>, 2024

The DPO Network welcomes the invitation to speak at this symposium. Given that this is a series of discussions led the Department of Public Expenditure and Reform it is particularly timely for us a Network to offer some thoughts on how the lived experience of disabled people can “strengthen the coherence of disability policymaking, to ensure more sustainable and effective policy solutions.”

### **About the DPO Network**

The DPO Network is an alliance of five national Disabled Persons’ Organisations in Ireland who share values and an agreed set of principles to work together. Based on these shared values and principles. we work together to help ensure that the CRPD in Ireland is fully implemented.

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

The DPO Network relies on disabled people’s lived experience, expertise and analysis and is 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.

### **How the UNCRPD must drive policy development**

From the perspective of the DPO Network, it is our view that since 2018 Ireland already has given a clear commitment to greater policy coherence since we ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). I want to use my remaining time to explore how that policy coherence can be advanced, and to specifically locate the role of Disabled Persons Organisations (DPOs) - nationally and locally - as the key drivers for how we practically implement the UNCRPD.

Firstly, without listing all fifty articles of the UNCRPD, I want to make specific reference to some wording that will resonate with us all as we begin to explore collectively how we build a coherence in policy formulation, policy implementation and State investment in our lives.

Firstly, and this is a point I will return to, the preamble notes that at its core the UNCRPD is about disabled people having “the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them”.

The general principles of the UNCRPD include “respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons” and “full and effective participation and inclusion in society”.

Therefore, at the core of the UNCRPD across all articles are embedded, essential vital values:

- Independence and self-determination for disabled people
- Full inclusion of disabled people in mainstream society
- Full participation of disabled people in decision making

From the DPO Network perspective, for us to progressively realise the UNCRPD, those values must guide and inform our collective role to establish coherence in Disability policy consistent with the UNCRPD and be our touchstone for policy development and implementation.

### **The role of DPOs as drivers of coherent policy development and implementation**

To fully realise the implementation of the United Nations on the Convention of the Rights of Persons with Disabilities (UNCRPD), effective policy making forums must be established to foster co-creative spaces to develop and implement effective policies.

Central to the realisation of the UNCRPD is the direct involvement of Disabled Persons Organisations (DPOs) in the design, delivery, implementation and monitoring of policy to promote our inclusion as per Article 4.3 and General Comment 7.

The DPO Network believe that one of the real reasons for the lack of coherence in disability policy making has been the exclusion of disabled people in local, regional and national fora. There is a lack of acknowledgment of the barriers that disabled people have and continue to experience in our day to day lives. These barriers range from a lack of awareness, negative attitudes, a lack of accessibility, not just physical access but also includes communications access to information in appropriate formats, through Irish Sign Language (ISL), etc.

Sadly, we all know and have experienced how silos prevent disabled people from having seamless interactions with the state and public services as they endeavour to have their needs met.

DPOs have only begun to become firmly established in Ireland. Our growth and development should inform how the State interacts with disabled people collectively and how DPOs should be prioritised in Statutory policy forums. The prioritisation of DPOs needs to be met with multi-annual investment to build the capacity and scope of DPOs to support the involvement of disabled people in policy making and to respond strategically to the implementation of the UNCRPD.

Due to the historic lack of investment in disabled people to develop collective autonomous DPOs, vague policy discussions in relation to disability in Ireland happened either through disability service providers, or individual disabled activists.

Disabled People working together in DPOs is a relatively new phenomenon in Ireland. DPOs are not just social spaces where disabled people meet (online or in-person). They are spaces where we critically reflect upon and analyse the social exclusion and oppression

disabled people experience through a social-model equality and human rights framework. DPO spaces are about not only identifying the issues we face, but also about identifying how systems and structures need to be changed for all disabled people to experience equity; strategically identifying what DPOs can and should do to drive this change.

DPOs can bring authentic analysis to policy discussions to inform change. While individual disabled people on local or national structures are often able to bring their own lone voice or individual experience or story to the fore, they are not supported or equipped to being an authentic cross-impairment collectively mandated intersectional voice. From a DPO Network perspective, reliance on the “lived experience” of individual disabled persons can lead to competing impairment-based discussions and also risks the creation of a “hierarchy of need”.

Where the State prioritises representation by individual disabled people it reduces the opportunity for real change. Having thirty competing voices at a meeting once a quarter where each individual brings their own issues will always lead to discussions that cannot deliver change.

Collective spaces for disabled people in DPOs allow for strategic thinking and for representatives to bring agreed actions and targets to the table. These discussions take time but allow for DPO representatives to come to the conversation supported by collectives that focus on developing a strategic analysis for the many rather than the individual. The current system of appointing individuals is based on outmoded thinking embedded within the medical model of disability and it creates a system that by design will not bring about change.

Prior to 2018 there have been no organic national DPOs working to bring the collective voice of disabled people to policy spaces at a local or national level. There has been a lack of a community development or social inclusion approaches to developing the authentic voices of DPOs.

However now, the emergence of genuine DPOs gives policy makers a structure for meaningful consultation and participation directly with the collective lived experience of disabled people. The development of DPOs also creates the opportunity to move from consultation to co-creation of policy, which makes for better policy and outcomes. Co-creation also facilitates genuine and equal partnership in policy development. Collective spaces for disabled people in DPOs allow for strategic thinking and for accountable representatives to bring agreed actions and targets into policy, planning, implementation, monitoring and evaluation discussions.

There are numerous examples of policy making spaces where the State recognises the primacy of collective autonomous spaces for people who experience social exclusion. In the development, for example of the National Strategy for Women and Girls, the National LGBT+ Inclusion Strategy or the National Traveller and Roma Inclusion Strategy, the State recognises the crucial role of representative organisations. The State does not randomly select individuals based on gender, sexual identity or ethnicity and ask people without out any mandate to suddenly represent entire communities and collectives. Strategy and structures must come before issues.

To build coherent policy that will result in greater inclusion of disabled people in Irish society with self-determination and control we need to recognise, support and resource the capacity of DPOs as collectives of lived expertise. Where the State funds disability services, they also need to recognise their commitments under the Public Sector Duty and the UNCRPD to support disabled people to be actively involved in local and national DPOs.

Service providers are there to provide services. Service providers, including umbrella groups of service providers have no mandate to create, resource or support disabled people in collective critical reflective spaces which rightfully belong to DPOs.

### **Co-Creation as a Process**

If we collectively accept that the driving values of the UNCRPD are those of independence and self-determination for disabled people; the full inclusion of disabled people in mainstream society; and the full participation of disabled people in decision making; we need to establish what co-creation as a process should look like.

I would like to think that I have established for you all that it has to be DPOs that are the focal point for coherent policy development, to bring disabled people's lived experience and collective analysis in terms of systemic change. Again, only DPOs, if resourced with the knowledge, skills and capacity have the mandate and values to create engagement that is often needed over a sustained time-period.

Alongside resourcing the capacity of DPOs the other much needed investment will be time. Co-creation as a process requires time not only for DPOs to develop our analysis and support our representatives through the process, but time to build relationships and trust with those tasked with policy development.

Policy makers are stretched, and time is often a luxury that can't be spared. But for a truly coherent inclusive policy approach, time is going to be one of the most important aspects. Civil and public servants need to be given time for spaces like to today - and beyond - to broaden their thinking and knowledge about disability from a social model/human rights perspective. We need time together to foster a shared understanding of the values inherent in the CRPD and how policies can give practical expression to progressively realising them.

DPOs will need time to get a greater understanding of the challenges of budgetary cycles, political cycles and the systemic inertia from the sheer scale and size of State investment in our lives. We note from the last DPER Symposium that the data estimates a figure of €6 Billion annually is being spent directly on our lives. How much of that budget was co-created with us? When as a collective were disabled people given time to give expression on whether that money was giving us greater autonomy in our lives? Has it led to us being further included as equals in society in all aspects of life - education, employment, politics, social inclusion, the arts and our well-being and health?

Time will be needed for State bodies to value the role of DPOs, and to recognise that not every group will want to participate in a process of co-creation. And for the DPOs who do want to build that partnership approach, we need to ensure that our authentic representatives do our DPOs justice and engage in a constructive dialogue for the progressive realisation of our rights.

Co-creation as a process requires honesty, transparency and at its core, bravery. We need to be brave to recognise the challenges. We need to be brave to admit that only by having a shared understanding of what we mean by disability can we truly have a sense of the scale of how to implement the UNCRPD in Ireland. We need to be brave to admit that no-one has all the answers, and part of finding the answers is to journey in partnership to explore them. We need to be brave to admit that mistakes will be made, but that with a shared set of values we can be brave to trust each other that change is not only essential but possible.

The recognition of co-creation as a process that works can be seen in multiple examples at the National Civic Forum. All attest to the challenges and the need to invest in processes to move from conflictual, attritional spaces where it is “us against them” towards more meaningful respectful relationships that can really design systems and structures that remove societal barriers.

In summary, I hope I have illustrated for you how together with the voices of disabled people through their DPOs we can use the UNCRPD to breakthrough silos and build policy coherence across the Disability Policy landscape. By embedding the role of DPOs into a process of co-creation we can begin to build new systems and structures that will fundamentally allow us to realise the values and intent of the UNCRPD. By having authentic collective voices at the table as equals to shape and direct policy, we can ensure that State investment in our lives will always be about our independence and autonomy, our inclusion in society and our participation in decisions about our lives. In short, we can finally demonstrate in an Irish context the practical application of the mantra of the international disability rights movement: “Nothing about us without us”.

Thank you

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