

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

8<sup>th</sup> April, 2024

Dr James Casey & Mr Peter Kearns.

Firstly, thank you to the members and staff of the joint Oireachtas committee on Disability Matters for inviting us to be part of this day and we are appreciative of your work and your collective work will make a difference. Thank you.

My name is James Casey and I am from ILMI - a Disabled Person's Organisation. as per the criteria outlined under General Comments of the UNCRPD but also in terms of social justice and historical movements. We were established in 1992 by disabled people for disabled people and we continue this legacy by harnessing the collective lived experience of disabled people in Ireland and facilitating, objective, authentic agency to their perspectives. As a collective organisation, we continue to build on the heritage of over thirty years of the Independent Living Movement and the work pioneered by many disabled activists and their vision for building a more inclusive society. Equally, as a national cross-impairment Disabled Persons Organisation, our values are at the core of how we work. Independent living is a desire for every person, disabled or non-disabled. It is not perhaps so much living on your own but rather living a life that is self – determined, whatever form that takes, but it is not a segregated life – whatever guise that is presented in. It is living and thriving and contributing to our communities. However, to reach these goals, we must co-create, collaborate and monitor the policies, rights and strategies that enable us to achieve them. This can only be achieved with Disabled people and their organisations.

DPOs are crucial conduits of the collective authentic disabled person's perspectives – the UNCRPD strongly promotes and recognises the primacy of the role of DPOs. Without authentic DPOs then we cannot move from single issue-based policy targets to more strategic and nuanced policy objectives. DPOs give policy makers structure of consultation but more importantly, they also give policy makers access to authentic, citizen generated data and vitally, the opportunity to move from consultation to co-creation of policy, which makes for better policy, which makes for better outcomes of opportunity for those it affects, which leads to a more healthy and inclusive society. Collective spaces for disabled people in DPOs allow for strategic thinking and for accountable representatives to bring agreed actions and targets.

Self-advocacy, where disabled people are supported to understand their rights within an equality framework, and are given the tools to have their voice heard is rightly seen as a progressive move away from models whereby disabled people were denied to have their own voice heard. Given the disabling nature of society, it is not surprising that disabled people have to continually advocate for basic supports. Often it is not clear on what supports are available, or what or how disabled people can apply for things like grants, Personal Assistant Services, assistive technology or even whether they can apply to return to education, employment or access housing.

Although individual disabled people can and do bring their own issues via self-advocacy to local or national structures they cannot bring an authentic cross-impairment, collectively mandated, intersectional analysis to develop or inform policies. 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. Otherwise it becomes a muddled jigsaw rather than a planned policy.

Disabled people need to be resourced to participate in and recognise and celebrate the value of collective empowerment in DPOs. Self-advocacy and advocacy cannot be managed or facilitated by service providers or their representative groups – this is incompatible due to power dynamics, not impartial and indeed against the ethos of the CRPD and the basic tenets of our democratic and social contracts.

Therefore having a structured, objective conduit of agency – such as a DPO like ILMI, enables disabled people to articulate their perspectives and lived experiences of issues in a strategic fashion, without a conflict of interest or a fear of reprisal.

The UNCRPD is clear on the prominent position of DPOs in advocating for disabled people and this is rather detailed in the articles, specifically Article 4.3, Article 29 (b) and expanded in General Comment 7.

What is less clear but also a concern is the misrepresentation of whom is speaking for the collective wishes and experiences of disabled people.

In the absence of mandated DPOs, many organisations and individuals have claimed to speak on behalf of disabled people contrary to the aims of the CRPD. This is perturbing, it is undemocratic and puts the social contract under yet more strain. The collective strategic input of mandated DPOs have to be recognised as how to realise the CRPD and build the participative democratic inclusion of disabled people in the design and monitoring of policies and practices to realise our rights. Allies are welcome and appreciated but they cannot speak *for* disabled people nor can they claim the mandate to do so – this puts our democratic and representational processes under question.

ILMI has a demonstrated track record and values driven collective ethos to be best placed, with our fellow DPOs, to facilitate and co-create meaningful policies and strategies. We have worked diligently with the collective welfare always during our work. The success of our ONSIDE project as well as the Strategies For Change initiative illustrated what we can do if given the resources. Both projects were unique, transformative, successful and led by disabled professionals – they, we believe, have contributed, like the rest of our efforts, to shift the paradigm of disability in

Ireland to a more modern, human rights and equality perspective. As a DPO, ILMI has endeavoured continually to make disabled people part of the greater conversation about diversity and true inclusion in our society and we recognise active ally ship with other marginalised and equality based organisations and groups.

But we are under resourced, undervalued and underrepresented. When we consider the disability industry in Ireland is funded to many billions in public money then we see how truly small our financial support is yet how big our impact has been. But we need support – long-term, multi-annual financial supports and otherwise. We have shown to be a catalyst for change and an authentic voice for disabled people, we have added to the discourse of social justice and environmental concerns. We have always tried to bring people together rather than apart and we have always done this with our values at the core of our work.

ILMI recognises, supports and values the intersectionality of disabled people and the multiple forms of discrimination they may face. Therefore, as a DPO, we share and promote common goals with Social and Climate justice groups, Women's Rights groups, LGBTIQ+ Rights organisations, Traveller Rights and Solidarity groups, Anti-Racism groups and people of colour groups. We do as it is the right thing to do, not by division or othering – but by active solidarity and collective agency with solution based policies based on the collective voice. This is how can achieve a more inclusive and fairer balanced society - we have more in common than we ever will have apart.

Thank you.