**Political Parties, Politicians and Disabled People:  
Building a shared analysis of Disability, Inclusion and the implementation of the UNCRPD**

**ILMI Position Paper July 2024**

**The Irish Political System and Disability**

The issue of “disability” has been an urgent political topic for decades. Politicians and political parties, regardless of political affiliation, have continually raised issues in relation to disability. The ratification of the UNCRPD represented a significant political milestone for Ireland. It placed obligations on the State to fundamentally realise the human rights of Disabled People and their full and equal participation in society.

With the creation of the Joint Committee on Disability Matters, there has been a welcome and sustained political conversation on the UNCRPD, as well as the development of political oversight on the implementation of the UNCRPD. This has also been reflected in political debates in other Committees and in both houses of the Oireachtas. “Disability” is being discussed and debated in a way politically that it has never been before.

ILMI as a national cross-impairment Disabled Persons Organisation (DPO) welcomes this increased discussion on the UNCRPD, but acknowledges that in order to realise the progressive implementation of the Convention, there is a real need for politicians and political parties to have a clear understanding of “disability”.

We believe in the importance of having a shared framing of “disability”, and we recognise the problematic nature of having voices claiming to speak in relation to “disability” not actually having a shared analysis on what they are referring to in using the word “disability”.

Being unclear about what we mean when we talk about “disability” means we will always lack collective clarity on what legislation, policies, systems and structures that will realise the aims and objectives of the UNCRPD.

**What do we mean by the term “Disability”?**

The word “disability” refers to people who have impairments experiencing a disadvantage caused by environmental or social barriers that disables them from fully taking part in mainstream activities. “Disability” is not the impairment. “Disability” is created by social organisations which take little or no account of people who have impairment labels. Society disables people by excluding them from mainstream social, cultural and economic activities.

**The Social Model of Disability**

The social model looks at how society is structured and how it disables people. It is not based on a person’s impairment, but rather focuses on barriers that exist in terms of attitudes, policy development, access or lack of supports that prevent people from participating in society as equals, with choice and control over their own lives. According to this model, it is society that disables people from achieving their hopes and dreams, not a person’s impairment.

**Medical Model of Disability**

The medical model individualises disability and promotes the idea that people are disabled by their impairments or impairment-label differences to non-disabled people. The medical model always focuses on people’s impairments from a medical perspective. In some ways, it still looks at what is “wrong” with the person, and does not consider the enabling supports the person requires throughout their lives.

Focusing on impairment and its cure or clinical stabilising focus creates low expectations and leads to people losing independence, choice and control in their own lives. Owing to its nature, the medical model cannot recognise the rights of Disabled People and assumes that Disabled People need to be “looked after” or “cared for”. The medical charity model dictates that mainly non-Disabled “experts” and “professionals” make decisions for Disabled People.

People informed by the medical / charity model language and thinking are limited to being focused on Disabled People’s impairments. A small number of people in the Republic of Ireland feel they are being politically correct by using the phrase “People with Disabilities”, which associates the word “disability” with just the person’s impairment and overshadowing impairment label, such as “person with impairment”.

ILMI promotes the social model term “Disabled People”, where people with impairments are “disabled” by society’s economic, cultural and socially created barriers.

It is important that politicians tasked with creating systems and structures realise that, at its core, the UNCRPD is framed by a social model analysis of disability. Whilst the person-first language of the CRPD reflects languages other than English, the intentions are very much about the removal of societal barriers.

**Political parties, politicians and Disability Equality: a commitment to learning and understanding**

Politicians are constrained by time. ILMI recognises that demands on politicians are huge: party demands, local constituency demands, Oireachtas demands, and multiple briefs to be immersed in. Most politicians recognise the need for change for Disabled People, but where are the opportunities to learn more about what the role of legislators should be in realising the UNCRPD?

Many politicians are directly engaged with and supporting disabled constituents in trying to navigate systems and structures.

There are additional challenges for politicians and political parties in relation to “disability”. Those challenges are magnified by the multiplicity of voices clambering, with good intentions, to talk about “disability”. A party member, politician or party official could engage with an individual disabled person with their own impairment life-course experience, or a parent of a disabled child, or a staff member working in a not-for-profit organisation. They could be lobbied by organisations that are directly funded by the State to provide “disability services”. Very rarely do they get a chance to devote valuable time to engage with Disability Equality as a concept and begin to see how to explore their own views on “disability” as a concept.

We need to recognise that how we think about “disability” has been unconsciously absorbed by all of us Disabled People and non-Disabled People) over our lives. It is influenced, consciously and subconsciously, by how we have historically treated Disabled People. State investment in “disability” has increased substantially over the last decade. However, inclusion isn’t just about money. How many of the services that the State are investing in have been asked for by Disabled People? How much of the money the Exchequer invests in “disability” is what Disabled People want and genuinely promotes inclusion?

The intentions to bring about change are clearly there. Politicians meet with individual Disabled People as constituents locally, or where individuals present to Committees, such as the JCDM (Joint Committees on Disability Matters). It is well-intentioned to listen to the individual life experience and to consequently support individual Disabled People to navigate complex social care systems and other supports to meet their needs. However, this does not bring about the long-term systematic changes required by the UNCRPD.

**Who gets to speak for “disability”?**

One of the challenges that politicians and political parties face is the multiplicity of voices in relation to “disability”. Parties, politicians and spokespersons may not realise that there are competing narratives on this issue. It is not uncommon for politicians to speak in the Oireachtas about their policies being based on lived experience. But whose experience?

Due to the historic lack of investment in community development approaches with Disabled People to develop collective autonomous DPOs, policy discussions in relation to disability in Ireland have either happened through disability service providers, or individual disabled activists or parental organisations.

Disability Service providers and organisations set up to “care for” or “look after” Disabled People never have supported Disabled People to be empowered. Within organisations, few are led by Disabled Persons, and these organisations lack a consistent analysis of what “disability” even means. To most of these organisations, their analysis on “disability” equates to their organisation needing more resources. They speak about inclusion as a concept, yet offer no meaningful insight into how inclusion can be achieved, as they lack an analysis led by Disabled People. More often than not, these organisations seek more funding to maintain the “status quo” of separation and segregation of Disabled People.

There are often instances where politicians speak in the Oireachtas Committee on behalf of the “disability community”. ILMI contend that politicians do not have a mandate to do so, unless they specifically raise concerns that are brought by DPOs. ILMI supports individual Disabled People to raise issues as constituents, and they should continue to do so. However, for systemic analysis and the implementation of the UNCRPD, politicians need to move from a reliance on individual lived experience towards collective strategic analysis provided by DPOs.

ILMI also recognises that many politicians not only have a passion for equality and inclusion, but that they have their own individual lived experiences. These can and often do include direct relationships with Disabled People. Whilst individual narratives often provide the spark for activism and political action, they cannot supplant the need for collective strategic analysis. The lived experience of a politician or their connection with a disabled friend, colleague or family member is not a substitute for collective strategic analysis.

Personal narrative connects us at an emotional and human level. However, if we take an analysis around employment, for example, we can recognise that a single worker’s story may resonate, but if we want to engage in longer-term thinking, we talk to unions.

Individual Disabled People can and should bring their own lone voice lived experience to the fore with their elected representatives. However, they are not supported or equipped to being an authentic cross-impairment collectively mandated intersectional voice to influence systemic change.  From an ILMI perspective, reliance on “lived experience” of individual Disabled People can lead to competing impairment-based discussions, which in turn creates a “hierarchy of need”.

Politicians and political parties need to build a Disability Equality analysis to determine what their role is in implementing the UNCRPD. Solely relying on individual Disabled People (or individual parents and so on) reduces the opportunity for real change. Having multiple potentially competing individual voices, where each individual brings their own issues, does not add to political analysis of the system and will not bring about the structural changes needed to implement the UNCRPD.

Collective spaces for Disabled People in DPOs allow for strategic thinking and for representatives to bring agreed actions and targets. Although these discussions take time, they allow for DPO representatives to come to the table supported by collectives to develop strategic thinking. Prior to ILMI’s establishment in 2018, there had been no organic national DPOs working to bring the collective voice of Disabled People to policy spaces at a local or national level. Until recently, there has been a lack of a community development social inclusion approach to the build-up of DPOs.

The medical and charity models of disability have further undermined any potential to invest in collective DPOs, with hundreds of impairment-based charities (often providing services) clambering for representative spaces. This creates a massive challenge on how to effectively consult and dialogue with Disabled People (in the past, consultation might have involved inviting some impairment-based groups at the expense of others), as opposed to having authentic DPO spaces to consult with from a genuine disability equality approach.

Thankfully, this is changing, and these changes will give politicians and political parties an authentic process to take time to develop their own analysis on what “disability” means, and how that influences political parties and politicians' commitment to realising the UNCRPD.

**Inclusion is not a neutral concept: with political change comes political challenges:**

There is a challenge for DPOs to engage politicians and political parties in deeper discussions to define what we mean by inclusion. Realising the UNCRPD is going to require investment and time beyond the electoral cycle.

Dismantling outdated systems is going to be politically unpopular, particularly at a local level. Removal of State-funded systems that are not consistent with real inclusion will meet with resistance from voters, often led by a strong parent voice. Politicians and political parties need to have an analysis of what change is and the direction of change.

Political parties and politicians have shown courage and an appetite for not shying away from popular resistance to change. The Marriage Equality and Repeal campaigns represent two scenarios whereby politicians and political parties had values-led discussions on why they supported systems change.

ILMI’s vision is an Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals. While we work towards this, we are all sadly too aware of Disabled People who continue to have their rights as human beings denied, especially those who are incarcerated in institutions and nursing homes rather than being given the opportunity to live their lives of their choosing with necessary supports in place.

Institutions are often established under principles of “looking after” people, providing them with safety. However, they completely reduce any choice for the people who end up being there. There is no choice in an institution and many institutions, through their dehumanising nature, are prone to abuse of those who are being sent there to be “looked after”.

Disabled People oppose institutions for all Disabled People. Institutions, once built and invested in, by their very nature create a demand for them to be filled.

Disabled People fear that where parents of disabled children lobby for residential institutions, it will increase demand, and that demand will inevitably lead to the “warehousing” of Disabled People, regardless of impairment or support needs.

**Disabled Persons Organisations (DPOs), Politics and realising the UNCRPD**

ILMI is a Disabled Persons Organisation (DPO). DPOs, unlike disability services providers, are led by and for disabled People. DPOs work on a cross-impairment basis with disabled adults. DPOs are about bringing Disabled People collectively together to bring about a more inclusive, equal society. DPOs are spaces for Disabled People, informed through an equality, human rights and social model of disability lens. DPOs believe themselves to be the voice of Disabled People, and therefore statutory and non-Statutory organisations should reach out to DPOs when looking to engage with the collective voice of Disabled People (including media, cultural, sporting, economic, employment and social inclusion dialogues).

There is a huge role for DPOs to play in terms of collective empowerment by creating spaces for Disabled People to build their shared, collective analysis of the systems that they want to bring that single, strategic voice for CRPD implementation to politicians and political parties, locally and nationally. This includes creating ways for Disabled People who access “disability services” to have the freedom to think about what their lives should be if they really had agency in their lives, and not just accessing what is convenient or available locally.

There is also a huge role in the future for DPOs to work with family organisations and organisations who work on the issue of “care”. Given the historical lack of investment in person-centred supports for Disabled People, regardless of impairment, parents have typically undertaken all support roles for their children, both as minors and into adulthood. These support roles (routinely referred to as care) can and do involve 24-hour support and provision of medical interventions. A very real concern for parents is that as they age, the only appropriate supports will be an institution. There is also an assumption that Independent Living is about living on your own, or that there is an implied hierarchy of impairment that means only some Disabled People can live independent lives.

Fundamentally, ILMI believes that in campaigning for investment in supports that meet the needs of Disabled People to be part of the community, the needs of Disabled People (regardless of impairment) and the needs of family carers will be met. Independent Living should be about every disabled person, regardless of the complexity of their support needs, having what they need to live their lives to the fullest of their potential. Appropriate supports will not only liberate Disabled People, but will also liberate their families. Disability Equality fundamentally is about equality and inclusion in society for all.

A similar level of political analysis is needed to implement the UNCRPD. DPOs recognise that systems need time to be dismantled as new systems are developed. However, they need politicians to work with DPOs to develop that clear, long-term vision for what we share as the type of Ireland we are working towards.

We need to recognise that investment in inclusion and equality is vital to realising the implementation of the UNCRPD. It also means that politicians need to have a vision for that change and robustly defend decisions to invest in systems like Personal Assistance Service as a priority over segregated services like day centres or respite.