



INDEPENDENT LIVING  
MOVEMENT IRELAND  
FREEDOM • RIGHTS • EMPOWERMENT

[www.ilmie.ie](http://www.ilmie.ie)

## **Independent Living Movement Ireland submission to the Special Committee on Covid-19 Response**

### **The Impact of Covid-19 on Disabled People's Lives: Challenges faced, Opportunities Created**

#### **1. Introduction to Independent Living Movement Ireland**

Independent Living Movement Ireland (ILMI) is a campaigning, national representative organisation that promotes the philosophy of independent living and to build an inclusive society. Central to the way we work is to ensure that policy decisions that impact on the lives of disabled people have to be directly influenced by those whose lives are directly affected.

Our philosophy can be summed up as: 'Nothing about us without us!' and 'Rights Not Charity'. Our 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.

As a Disabled Person's Organisations (DPO), we are highlighting the key issues faced by disabled people during the Covid-19 but also the creative collective spaces that disabled people built to reduce social isolation when social distancing.

#### **2. Process of developing this submission**

ILMI as a DPO always creates spaces for disabled people to generate policy submissions based on the lived experience of disabled people across the country. In order to develop this Covid-19 submission, we held a facilitated Zoom on the 25<sup>th</sup> June and asked our members a series of questions. This submission represents the discussion held and the views of disabled people.

### **3. Positive Opportunities created and developed by disabled people during the Covid-19 crisis**

Contrary to the general narrative, many disabled people have found positives in how the country responded collectively to the challenges we all faced during the Covid-19 pandemic and specifically how disabled people responded creatively to build connections and work in different ways to reduce social isolation by building online communities.

Many disabled people have found the use of video conferencing technology, such as Zoom, to connect with other disabled people liberating. ILMI online spaces, which included peer support and platforms to discuss policy, activism and even creative spaces such as a film club, as well as county-specific discussion spaces for disabled people in Clare, Donegal, Leitrim, Sligo, Longford, Cavan and Monaghan. There were also weekly workshops on topics such as mindfulness, yoga, nutrition, independent living, effectively managing a Personal Assistance Service (PAS), photography and drawing.

These spaces allowed hundreds of disabled people to access online training and social spaces to get to know other disabled people, build social networks and learn from each other as peers. Use of Zoom has allowed everyone participate: disabled people no longer need to worry about whether venues or the built environment is accessible, accessible transport or a lack of PAS hours.

The experience of ILMI members using zoom to connect and reduce social isolation highlights for disabled people that high speed broadband now is an essential tool and assistive technology needs to be there to support this. It is important to keep people connected.

Peer support spaces became enormously important for disabled people to discuss the impact of Covid-19 on their lives and the supports they use to live independent lives, including Personal Assistance Services.

Online spaces gave disabled people a voice: using ILMI spaces they not only supported each other through Covid-19 but also fed directly into ILMI policy development, including communications to the NPHET to voice their concerns and direct how supports should be delivered to disabled people.

ILMI through its INTERREG funded cross-border initiative was perfectly placed to provide direct IT support to disabled people in the border counties. That approach allowed a targeted approach that could be replicated across the country.

Technology has opened up opportunities for disabled people to work from home and in one instance, one of our members who never had an opportunity to work gained employment via online technology.

Social distancing measures in public spaces, such as shops, in some instances has impacted positively on accessibility.

Disabled people also welcomed the use of ISL in NPHE briefings and want to see that this becomes the norm that public information is fully accessible.

#### **4. Challenges for Disabled People during the Covid-19 crisis**

For disabled people, often the language and discussion around disability reverted to a medical view of disability. Disabled people were repeatedly seen as high risk, regardless of their impairment and cocooning was imposed upon us, removing any agency or choice as independent adults. Those disabled people who did continue to go about their lives often solicited reactions from the public with comments such as “why are you out”? These comments are based on the medical narrative that place all disabled people as being “at risk”.

A huge issue for disabled people was the continued exclusion of Disabled Person’s Organisations (DPO) from discussions in policy development and hence denying disabled people from having their voices heard. Disability Service providers spoke on behalf of disabled people without having a mandate to do so. Often discussions about disability were led by family members, which allowed our lives to be publically seen as a “problem” for families; our lives are spoken about in terms of a “burden” for families with no regard for our dignity, our agency or what we as disabled people want. We as human beings are often an afterthought in these discussions.

A recurring theme in ILMI discussions was the lack of consistent, clear information across all CHO areas in relation to disability services and guidelines on delivery of services such as the PAS during Covid-19.

There has also been huge changes in the provision of PAS across the country, with no standardised approach across CHO areas. For some disabled people Covid-19 has meant complete loss of independence, moving from their homes into family homes. Often service providers have not made any contact with disabled people they provide services to. PAS hours were cut for many leaders and the crisis was used as a chance for them to cut hours and the roles a PA could carry out were restricted, such as PAs being told they could not drive disabled people whereas they could pre-Covid-19.

Restrictions of people in accessing health services meant that no PAs were allowed into hospital with disabled people, regardless of our needs during the crisis. Hospital appointments were postponed and for many they are crucial to maintain a quality of life. At the start of the crisis, the lack of access to PPE for leaders and PA’s and in general was a huge issue. We need to learn lessons from this should there be a second wave, disabled people’s needs in their homes must be prioritised.

Public transport being reorganised will have huge impacts on disabled people's daily lives. The reorganising of the transport system makes it difficult to use for disabled people. In the re-opening of cities and towns, the independence of disabled people cannot be sacrificed in "greening" transport systems. Inclusion and access are part of the development of sustainable transport infrastructures.

Disabled people are fearful of the compulsory wearing of masks on public transport. This may lead to disabled people who can't wear a mask being berated or treated as "special" or the general public being "suspicious" of us.

Whilst the use of technology allowed more flexible working environments that were conducive for some disabled people, there is a fear that rather than working environments becoming more accessible and supports put in place to support disabled people to work in an inclusive, accessible workplace that disabled people will only have the option to work remotely and be kept "out of sight, out of mind". Flexible working conditions are not a substitute for an inclusive, equal and accessible Ireland where disabled people being employed in all workplaces becomes the norm.

Masks are not accessible for those with communication barriers. Policy makers need to be aware of this and in the provision of information there needs to be approaches that allow lip reading and communication. Similarly, not all public health information, especially at the start of the crisis, was fully accessible.

## **5. The potential opportunities created by the Covid-19 Crisis**

Within every crisis there is an opportunity. Members recognised that ILMI as an organisation responded creatively to the crisis to create numerous online spaces to connect disabled people and have continued to do so. As one member said "I would be lost without ILMI during this crisis". This creative response shows that disabled people have the ways and means of doing things. For example, the Covid-19 pandemic "forced" us to connect online but it has broken down geographical and physical barriers for disabled people. Online engagements are accessible to most: it removes the challenge of inaccessible transport and the lack of PAS hours.

Connecting virtually in Zoom brought an opportunity to find new ways of bringing disabled people together through zoom gatherings. This connection brought to the fore the absence of peer sharing, learning and peer support for disabled people from other disabled people in recent times. A sense of disabled community was created in our meetings, which was important, in particular, to those disabled people who never before regarded themselves as being offered the opportunity by service providers to debate with other disabled people on what was negatively impacting on their lives, or learning from disabled people about solutions and coping skills they had used to achieve increased independence in their lives.

Non-disabled people during social isolation got a “tiny taste” of how many disabled people live their lives- confined to their homes due to lack of PAS hours, inaccessible built environments and lack of transport. Hopefully this new understanding and insight will drive and direct policy towards inclusion for disabled people.

Looking towards the future, disabled people want to have full control over their supports and services to make the decisions about our lives. There is a huge opportunity for disabled people to have choice and control, for example for disabled to begin to self-direct their services.

## **6. Additional observations from disabled people for the Covid-19 Response Committee**

It was obvious that there was not a state funded DPO consulted during this crisis to listen to the lived experience of disabled people. Should there be a second wave and new public health measures developed, there needs to be a process to engage with DPOs who represent the lived experience of disabled people.

Due to the lack of engagement with DPOs, the state dealt with organisations of disabled family members and the narrative was “how awful their life is” which reinforces negative representation of disabled people, feeding into the medical model of disability. Disabled people’s voices need to be central to discussions on disability: “Nothing About Us Without Us”. The presence of a DPO in these discussions would ensure there is no return to a medical narrative of disability and talk of “protecting the vulnerable” or to remove disabled people’s autonomy and agency by forcing us to “cocoon”.

Engagement with DPOs led by the lived experience of disabled people will allow Ireland respond to public health emergencies to ensure standardised approaches, accessible information and provision of PPE.

The National Disability Authority (NDA) and its centre of excellence in terms of Universal Design needs to be utilised in design and delivery of services.

There will and is physical and emotional impacts of this crisis on us. For example, we no longer have the same access to services such as OT or mainstream services such as Library or the pool. For some the pool was the only movement or physical activity we got and many are not feeling as “fit”. Many of our appointments were cancelled, and some disabled people are anxious about public spaces which limits our choices and lifestyle. Many specialist therapy has not been available during the Covid-19 crisis.

Whilst technology can be liberating, it is not a replacement for real inclusion and participation in all aspects of society. It is not a replacement for accessible transport, accessible built environments and a well-resourced PAS service. Disabled people having freedom, choice and control over all aspects of our lives to fully participate in an inclusive

society as equals requires these supports to be put in place. Connection through technology should be an addition to these measures, not a substitution for real inclusion.