



INDEPENDENT LIVING
MOVEMENT IRELAND

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ILMI submission to the Joint Committee on Disability Matters

[Independent Living Movement Ireland \(ILMI\)](http://www.ilmi.ie) is a campaigning, national Disabled Person's Organisation (DPO) that promotes the philosophy of independent living and seeks 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 must 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.

Independent Living is about having the freedom to have the same choices that everyone else has in housing, transportation, education and employment.

Independent Living is about choosing what aspects of social, economic and political life disabled people want to participate in. Independent Living is about having control over your life, to have a family, to get a job, to participate socially and to realise your goals and dreams.

As a Disabled Persons Organisation (DPO), ILMI is well-placed to engage in direct consultation with disabled people to relay the lived experience of disabled people and make a robust submission to the committee on Disability Matters. The lived experience of disabled people is vital to informing policy that impact on our lives and to highlight what is working and areas where improvement is needed.

ILMI welcomes the commencement of this Committee and want to thank Michael Moynihan TD the Chair, Minister O'Gorman, Minister Rabbitte and the members of the Committee for their commitment to advancing the human rights of all disabled people in Irish society.

The UNCRPD at its core is framed through an understanding of disability known as the social model of disability. From ILMI's perspective, it is vital that the committee on Disability Matters has a clear and full understanding of what the social model of disability is and how it should inform their discussions on policy development and implementation, participation of disabled people in an inclusive society and the direction of resources to ensure that disabled people have control over their lives to participate in society as equals.

What is 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, it is focussed on the 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. In this model it is society that disables people from achieving their hopes and dreams, not a person's impairment. The social model informs all aspects of the work of Independent Living Movement Ireland.

ILMI's work is to develop policies and campaigns based on disabled people's lived experiences in order to remove barriers that restrict life choices for disabled people. When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives. Barriers are not just physical. Attitudes found in society, based on prejudice or stereotypes (also called disablism), also disable people from having equal opportunities to be part of society. Disabled people developed the social model of disability because the traditional medical model did not explain their personal experience of disability or help to develop more inclusive ways of living. The social model of disability informs key International Conventions such as the UN Convention of the Rights of Persons with Disabilities (UNCRPD) and is in contrast to the "medical / charity model" of disability.

The **medical / charity model** individualises disability and promotes the idea that people are disabled by their impairments or differences. 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 not what the person needs. It creates low expectations and leads to people losing independence, choice and control in

their own lives. The medical / charity model never recognises the rights of disabled people and assumes that disabled people need to be “looked after” or “cared for”. Under the medical / charity model professionals make decisions for disabled people.

Language and representation of disabled people

Independent Living Movement Ireland recognises that language is a very powerful and evocative tool. Therefore, the language and terminology used in this submission has been carefully chosen to reflect the values of equality and empowerment which is at the core of this organisation. The term ‘disabled people’ has been used throughout the submission in accordance with the UPIAS classification of disability and impairment which has been developed by disabled people themselves (UPIAS 1976). Where disabled people are referred to in the submission this should be understood to include all disabled people, including those with learning difficulties, mental health difficulties and sensory impairments.

UNCRPD articles 4.3 and 29 B

The UNCRPD makes specific references to state party commitments to ensure disabled people are effectively involved in all policy forums which article 4.3 and 29. B of the convention state. Article 4 – General obligations 3 states “ In the development and implementation of legislation and policies to implement the present convention, and in other decision-making processes concerning issues relating to persons with disabilities, state parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations” – see more [here](#)

While article 29. B is “To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs” including firstly “participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties” and secondly and importantly “forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels”.

For far too long disabled people have been excluded from participation in decision making structures at all levels. Disabled people want to have their views heard and valued to advance equality, social justice and sustainability through active engagement in decision-making, rebalancing of power in this process, and investing resources to support this engagement. In ILMI's election manifesto we called on all political parties to commit to direct engagement with genuine Disabled Persons' Organisations (DPOs) and to ensure that they are resourced so that we can engage effectively in policy development at all levels.

“Nothing about us without us”: the role of Disabled Persons’ Organisations (DPOs)

DPOs, unlike disability services providers, are led by and for disabled people. It is vitally important that this forum is where we need to have our contributions heard, represented and recognised in policy development.

As stated in our opening remarks Independent Living is about having the freedom to have the same choices that everyone else has in housing, transportation, education and employment. Independent living is about choosing what aspects of social, economic and political life people want to participate in. Moreover, funding is the true recognition of commitment and support of the independence of DPOs in our campaigning work.

For further information see our election manifesto [here](#)

Article 19 Living independently and being included in the community

This is about ensuring disabled people can live in and be part of their community and have the same choices as everyone else about where they live and who they live with. This includes making sure that the right services are available in the community to make this possible. For some disabled people Independent Living is best achieved by the employment of Personal Assistants. The **Personal Assistance Service (PAS)** is a tool that allows us to live independently. The Personal Assistance Service enables us to do all the tasks that we cannot do for ourselves. It provides us with the freedom and flexibility we need to live our lives as we choose.

A Personal Assistant (PA) is hired to assist us with a range of day-to-day tasks that we cannot physically do for ourselves. With a Personal Assistance Service (PAS) we are in control and direct the PA to carry out tasks both inside and outside of the home, including personal care, domestic duties, assisting in day-to-day tasks such as shopping, support in the workplace or socialising. A PA does not “look after” or “care for” us. We delegate these tasks to our PAs and in doing so take back control of our lives.

A distinct benefit of a Personal Assistance Service is that it reduces our dependence on our family and friends. The confidential relationship that develops between our PAs and us allows us to maintain a private life and our dignity. The Personal Assistance Service is often the difference between existing and living for many of us.

ILMI has a #PASNOW campaign which received a unanimous Dáil motion passing in November 2019. It is important to note there is currently no legal right to Personal Assistance Services (PAS) in Ireland. ILMI identified five key steps that we could work on to achieve a right to a Personal Assistance Service (PAS). See our #PASNOW campaign summary [here](#). ILMI has also developed a document about “Achieving a right to a Personal Assistance Service in Ireland”. Please see our summary document [here](#) and the full document [here](#).

Section 6 of the National Disability Inclusion Strategy (NDIS) (“Person-centred disability services”) and specifically “Achieve maximum independence” (Actions 69 - 71) in the NDIS do not make any reference to the Personal Assistance Service, despite it being central to many disabled people’s lives and independence. Many disabled people are unable to avail of a Personal Assistance Service or only have access to a limited service or a home help service based in their home as opposed to a Personal Assistance Service which would allow them to have full control of their lives.

ILMI welcome the increase in Personal Assistance funding in the budget and according to information submitted by the HSE to the Committee on Public Petitions in 2017, 1.51 million service hours were delivered to 2,470 people. However, these figures show that 84.44% of disabled people who received a Personal Assistance

Service received less than three hours per day on average, with 44.41% of disabled people in receipt of an average of 42 minutes per day. It is clear that anyone who receives an average of 42 minutes per day is not going to be able to live independently, access education or employment or become involved in meaningful social engagement. Disabled people with reduced services of this nature will become trapped in their own homes without the chance to interact and will be prone to isolation and depression.

Through a nationwide consultation with our members it is clear that some service providers are moving away from the original model started by the Center for Independent Living in 1992, which was based on disabled people themselves directing their Personal Assistance Service to enable them to live full, independent lives. Many feel the Personal Assistance Service is moving towards a system focused on compliance, regulation and bureaucracy. Given that many other actions in the NDIS and articles outlined in the UNCRPD relate to employment, participation, education and inclusion, the Personal Assistance Service (PAS) is often a vital piece of the “independent living jigsaw” for many disabled people to have the freedom, choice and control over their lives. See ILMI’s submission to the Mid Term Review of the National Disability Inclusion Strategy (NDIS November 2019) [here](#)

Disabled people and housing

Ireland is currently in the midst of a housing crisis. At our annual conference in September 2018 it was noted by members that housing has always been a crisis for disabled people due to the lack of accessible housing, the lack of visibility of disabled people in discussions on housing and homelessness, and the pervasive nature of the medical / charity model of disability which leads to institutionalisation of disabled people.

Disabled people are more than twice as likely to report discrimination relating to housing and over 1.6 times more likely to live in poor conditions, such as living in damp housing, lacking central heating or living in an area with neighbourhood problems. Disabled People are also particularly over-represented in the homeless population: more than one in four homeless people are disabled people. Housing is part of the “independent living jigsaw” and article 19 of the UNCRPD. Housing is also

addressed in Section 7 of the NDIS (“living in the community) specifically actions 93 - 94 and action 96.

“A Time to Move On from congregated settings” (actions 93 and 94 NDIS) as a strategy is predicated on supports being in place for disabled people to live independently, such as the Personal Assistance Service, but it also requires investment in accessible and universally designed housing. The main reference (action 96) to housing for disabled people in the NDIS is the National Housing Strategy for People with a Disability (NHSPWD) 2011 to 2016. This was the Government’s strategy to specifically address the housing needs of disabled people over the period of 2011 to 2016. Building on the Programme for Partnership Government commitment to meet the housing needs of disabled people, the NHSPWD has been affirmed in Rebuilding Ireland (2016) and extended to 2020 to continue to deliver on its aims.

The vision and strategic aims of the NHSPWD are to achieve a coordinated and integrated approach to meeting the housing needs of disabled people at local level. From this, Housing and Disability Steering Groups (HDSGs) have been established in all local authority areas. These are chaired by the Directors of Housing with membership including the HSE and disability representatives; although there is lack of clarity whether these representatives are disabled people or people working in organisations that provide services to disabled people.

Each HDSG is required to have prepared a local Strategic Plan on housing disabled people for its own City / County area. ILMI contacted all local authorities and secured all strategic plans of all local authorities, with the exception of Carlow County Council and Laois County Council. Our analysis shows that the plans developed locally as part of the National Plan for Housing People with Disabilities 2011 - 2016 vary wildly. Some plans do not even have the basic components of a plan that could possibly deliver housing for disabled people (assessment of need, timelines, targets, budget required). This needs to be addressed as a matter of urgency.

ILMI is concerned that a National Strategy which was meant to be completed in 2016 has not been reviewed for its effectiveness and implementation and has been

affirmed to extend to 2020 as part of Rebuilding Ireland Action Plan for Housing and Homelessness. In consultation with ILMI members, significant concerns were raised about Rebuilding Ireland's reliance on the HAP scheme and private rented accommodation as this more often than not will be unable to meet the access needs of disabled people. Again, housing and the supports for independent living need to be addressed so disabled people can live in their communities like other citizens of Ireland. ILMI made a submission to the joint Oireachtas Committee on Housing in June 2019. For more information read it [here](#).

Disabled people and employment

(Article 27 UNCRPD Work and employment and Article 28 adequate standard of living).

A report published by the [ESRI](#) in 2018 found that disabled people in Ireland are four times less likely to be employed. The report found that, despite wanting to work, disabled people are less likely to get a job. In 2017, 31% of working-age disabled people were at work compared to 71% of non-disabled people. Disabled people are less likely to get a job for numerous reasons including barriers that exist such as accessibility to information (for those with visual impairment) and accessibility in the built environment, no access to adequate supports such as assistive technology and personal assistance services (PAS).

Due to these barriers to accessing education and employment and with the added costs of disability, disabled people are one of the groups most at risk of deprivation and consistent poverty. Research from the [Survey on Income and Living Conditions \(SILC\)](#). In 2016, 21.0% of the population experienced two or more types of enforced deprivation. Whilst information is not detailed, the SILC showed in comparison those who were not at work due to illness or disability (46.7%) also had high deprivation rates in 2016. The consistent poverty rate in 2016 was 8.3% but the highest consistent poverty was found to be among individuals not at work due to illness or disability (26.3%).

In the recent budget ILMI called on the government to allocate resources in order to meet commitments to implement policies such as the Comprehensive Employment Strategy for Persons with Disabilities, and targets set in the National Disability

Inclusion Strategy 2017 - 2021, including an increase of the public service employment target from 3% to 6%.

Social inclusion and digital divide

Since the pandemic hit in March 2020 and 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 created 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, Galway and Offaly. 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 to participate: disabled people did not need to worry about whether venues or the built environment were accessible, did not need to worry about organising transport or a lack of Personal Assistance Service 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 NPHE to voice their concerns and direct how supports should be delivered to disabled people.

ILMI through its INTERREG funded cross-border initiative ONSIDE was perfectly placed to provide direct IT support to disabled people in the border counties. That targeted approach could be replicated across the country, with appropriate investment. 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 through online technology.

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 and cannot be a substitute for an inclusive, equal and accessible Ireland where disabled people being employed in all workplaces becomes the norm. As a Disabled Person’s Organisations (DPO), we highlighted 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. Read more [here](#)

ILMI recognises that COVID-19 has changed the world we live in and the requirements for social distancing as a public health measure will be something that everyone must observe for the foreseeable future. As outlined in our submission [“Enabling the City to Return to Work Interim Mobility Intervention Programme for Dublin City”](#) there is concern regarding how people will be able to travel and move around our cities. Public Transport plays a significant role too in the “independent living jigsaw” and while this submission above is Dublin specific we as a Disabled Person’s Organisation (DPO) believe there is a huge concern regarding how disabled people will be impacted in everyday life and how they travel around our cities. We understand that to safely meet social distancing requirements, a number of changes have been made where additional space for pedestrians is needed.

However, plans must be inclusive and positively impact on disabled people's lives. ILMI recognises that the COVID-19 pandemic necessitates rapid temporary changes in order to facilitate people returning to work whilst maintaining social distancing and to promote, where possible, safe, sustainable pathways for people to access. In this submission ILMI welcomes the commitment that "the proposals will not diminish or reduce any of the accessibility arrangements already in place" and the commitment to dialogue as part of the implementation stage "to facilitate more focused input in relation to accessibility issues into individual proposals", which will be needed to ensure that any well-intended measures do not pose risks to disabled pedestrians or reduce access or inclusion for disabled people in Dublin City. For more information read [here](#)

Reproductive justice

ILMI recognises that being part of an inclusive society is one where disabled people have the choice of how they live their lives. Often disabled people are denied the right to make reproductive decisions, including decisions about fertility, contraception, pregnancy, childbirth and parenting. In many countries, there are specific laws criminalising sex with disabled people. There are also higher rates of sterilisation and forced abortion among disabled women and girls than non-disabled women. UNCRPD Article 23 - **Respect for home and the family** affirms that state parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships. The article also states the rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age appropriate information, reproductive and family planning education, and the means necessary to enable them to exercise these rights are provided. Article 6 Women with disabilities and article 25a Health are also significant.

As mentioned above in the "social inclusion and digital divide" section of our submission ILMI responded collectively to the challenges we all faced during the Covid-19 pandemic and specifically disabled people themselves responded creatively to build connections and work in different ways to reduce social isolation by building online communities. Examples of those online communities that ILMI

supported includes a disabled women's group and Full Spectrum: Disabled LGBTI+ Peer Network which meets bi-weekly. ILMI have also been involved in hosting spaces for disabled people to feed into the NUIG CDLP research project Re(al) Productive Justice. The key goal of this project is to make visible the experiences of disabled people in Ireland seeking reproductive justice.

Participation in cultural life, recreation, leisure and sport

ILMI recognises that part of an inclusive society is one where disabled people have the choice of how they live their lives and that society is structured to ensure supports are in place for people to decide what activities they want to be involved in. Article 30 **Participation in cultural life, recreation, leisure and sport** states that all policies should ensure that disabled people participate on an equal basis "in recreational, leisure and sporting activities" and state parties should take appropriate measures to ensure this inclusion is resourced. Examples of these facilities / activities that ILMI supported is the The Lough Ree Lake Access for All boat on the river Shannon and the Cavan-Leitrim Greenway which both represent a model of inclusion to ensure that disabled people can participate in sporting and tourist activities as part of an Inclusive Ireland. These projects build Ireland's capacity to fulfill its commitments to implement the UNCRPD to the fullest. Both projects seen best practice being implemented by ensuring that the development consulted directly with disabled people to ensure that their voices were heard and represented and the developments were fully accessible and with maximum standard and best practice and the forefront.

Recommendations:

- In developing a clear terms of Reference for the Joint Committee on Disability Matters, members of the Committee should prioritise inputs from disabled activists on the social model of disability. This will ensure that the language, framing, and direction of the Committee and the monitoring of key legislation, policy and implementation of the UNCRPD is not based on an outdated medical / charity model of disability.
- Ensure that all decisions in relation to disabled people's lives are made in direct consultation with disabled people.

- Legislate for a right to Personal Assistance.
- Commit to Investment in accessible public housing.
- Ensure that mainstream social inclusion supports include disabled people and that best practice developed by ILMI in using technology is supported to be rolled out across the country.