



INDEPENDENT LIVING
MOVEMENT IRELAND

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Independent Living Movement Ireland submission to the Mid Term Review of the National Disability Inclusion Strategy (NDIS)

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. As one of the few Disabled Person's Organisations (DPO), we are uniquely placed to make a submission on midterm review of the National Disability Inclusion Strategy.

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.

The Social Model of Disability and the NDIS

The social model of disability says that disability is caused by the way society is organised, rather than by a person's impairment or difference. It is based on concepts of rights, dignity, autonomy and equality.

The social model of disability looks at ways of removing 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 People with Disabilities (UNCRPD) and is in contrast to the **Medical / Charity Model** of disability. This model individualises disability and promotes the idea that people are disabled by their impairments or differences. The medical model 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”. The medical / charity model has professionals make decisions for disabled people.

Central to the NDIS mid-term review is for all stakeholders to recognise that the models of disability will intentionally and unintentionally create frameworks for how policy is developed and delivered. ILMI believes that for the NDIS to really bring about inclusion for disabled people, it needs to promote and develop a clear framework and vision based on the social model of disability.

Language and Disability

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.

1. What is working in the NDIS?

The NDIS provides a cohesive and comprehensive overview at an inter-departmental level of statutory supports and policies relating to disabled people and their lives. It brings an overview of legislative, policy development and implementation and service delivery in a single document with indicators that can be monitored for implementation.

There is clear commitment from the Minister with special responsibility for Disability Issues Mr Finian McGrath TD, members of the Disability Steering Group (DSG), officials from the Department of Justice and Equality and other Government departments to ensuring the NDIS is effective.

Since the development of the strategy, a number of actions have been progressed, such as:

- Action 47, Implementation of the Comprehensive Employment Strategy.
- Action 49, increase targets from 3% to 6% recruitment of disabled people in public service, with figures from NDA showing considerable success.
- Action 54, Make Work Pay working group recommendations and reforms to support disabled people to take up employment.
- Action 91, The Personalised Budget Task Force report published and call for first participants in demonstration models for direct payments announced October 2019.
- While progress has not been ideal, ILMI recognises that there has been considerable engagement between the NTA, Irish Rail, Bus Eireann and local authorities with

disabled people on making public transport accessible, notwithstanding continued access issues and need for advance notice time to be addressed over the remainder of the NDIS.

2. What is not working in the NDIS?

Overarching concerns about NDIS

In being a comprehensive overview of all Departmental policies and actions relating to disability from 2017-2021, it is hard to see how all 114 actions can be carried out. The wide nature of the NDIS also means that it is unclear which actions are to be prioritised and how these will be implemented. This can lead to a feeling that no actions are being prioritised or that any progress is being made on the ground. Many ILMI members feel that actions are too vague (for example, action 31 “we will consider how best to build on and progress work completed to date to facilitate smooth transitions into, within and out of education..”)

There are also concerns where actions are a continuation of existing policies (see actions 35, 36, 38, 48, 57, 63, 66, 67, 68, 88, 93 and 95) that there needs to be some evaluation of what progress has been made to justify their continuation and whether they are still being resourced, implemented and evaluated.

In providing a complete overview of disability policy development and service delivery comprising 114 actions by its very nature the NDIS becomes too big, with too broad a focus and not enough tangible actions to be clearly implemented, monitored and evaluated for impact and success.

ILMI feels that in order for the NDIS to be effective it needs to deliver on core aspects of inclusion. 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.

ILMI also feels that all aspects of the NDIS should be available in Braille and audio as PDFs are not accessible for the visually impaired.

Specific Actions that seem to have not progressed

Independent Living and the Personal Assistance Service

Central to many disabled people having control and choice over their lives is the Personal Assistance Service (PAS). However, Section 6 (“Person-centred disability services”) and specifically “Achieve maximum independence” (Actions 69-71) do not make any reference to the Personal Assistance Service, despite it being central to many disabled people’s lives

and independence, and that many disabled people are unable to avail of a PAS or only have access to a limited service or a home help service based in their home as opposed to a PAS which would allow them to have full control of their lives.

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 PAS 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 PAS to enable them to live full, independent lives. Many feel the PAS is moving towards a system focused on compliance, regulation and bureaucracy (for more information see <https://ilmi.ie/wp-content/uploads/2018/10/ILMI-Personal-Assistance-Campaign-Leaflet-min.pdf>).

Given that many other actions in relation to employment, participation, education and inclusion rely on disabled people having access to a PAS, this is a huge concern for ILMI which would need to be a core focus for the work of the NDIS for 2020 (see below).

Independent Living 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 for disabled people, 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 disabled¹

Housing is addressed in Section 7 (“living in the community) and specifically actions 93-94 and action 96. “A Time to Move On” (actions 93 and 94) as a strategy is predicated on supports being in place for disabled people to live independently, such as the Personal

¹ “Discrimination and Inequality in Housing in Ireland” IHREC and ESRI report <https://www.ihrec.ie/discrimination-and-inequality-in-housing-in-ireland-set-out-in-new-research/>).

Assistance Service (see above), but it also requires investment in accessible housing. Worryingly the main reference (action 96) to housing for disabled people in NDIS is the National Housing Strategy for People with a Disability 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 Ireland² (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.

In developing a submission to the Oireachtas Committee (<https://ilmi.ie/wp-content/uploads/2019/07/ILMI-Submission-to-the-Joint-Oireachtas-Committee-on-Housing-June-2019.pdf>), 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, huge 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.

4. Are there any actions that are no longer relevant and can be removed?

Rather than remove actions, which would be emotive, ILMI believes that as the national strategy on inclusion, specific broad aims (as below) should be prioritised. Specific consultative committees as per the Disability Act should take the time to deliver on department specific actions rather than the NDIS.

² http://rebuildingireland.ie/Rebuilding%20Ireland_Action%20Plan.pdf

For ease of reading and to save duplication, we have amalgamated questions three and five.

3. What are the priorities for the NDIS during 2020 and 2021?

5. What are the top three actions that should be prioritised in order to facilitate compliance with the UN Convention on the Rights of Persons with Disabilities?

Article 19 of the UNCRPD the Right to Live in the Community:

As per sections two and three of this submission, ILMI believes the focus on Achieving maximum independence and living in the community, should be prioritised in order that Ireland is compliant with Article 19 of the UNCRPD.

Section 6 Person-centred disability services, Achieve maximum independence: Actions 69-71

The Personal Assistance Service (PAS) is conflated with and funded from the same budget as Home help by the HSE. The PAS has no standardised assessment of need and it needs stand-alone investment.

A recent motion passed in Dáil Eireann to legislate to provide for the establishment of a Commissioner for Independent Living within the Department of Social Protection tasked with the following functions:

- To consult with the disabled community to devise a universally accepted definition of the Personal Assistance Service, placing disabled people at the centre of any service provided and directed by individuals to meet their needs to live independent lives.
- To facilitate the separation of the Personal Assistance Service from Home Help Hours and Home care and develop a strategy to oversee the transition of PAS to come under the remit of the Department of Social Protection and under the Commissioner for Independent Living.
- To address the current lack of understanding of the term “Personal Assistance service” which has led to inconsistencies in standards and quality of service provision in this country and across HSE areas.
- To seek an end to the practice of assigning Home Help Hours instead of a PA service.
- To ensure individuals do not end up with a service that does not support independent living as per the PA model of service and risk individuals being removed from any waiting list for PA services when accepting Home Help Hours instead.

- To establish a National Independent Living Strategy to include a roadmap towards the increasing of a ring-fenced budget for Personal Assistance Services so as to enable disabled people to lead real independent lives.
- To introduce a single standard assessment of need across all HSE CHO areas. This must include the provision and support for independent assessment of need as per the Disability Act 2005 and the creation of systems that allow for portability of services across CHO areas, meeting the social, personal and employment needs of those who avail of the Personal Assistance Service, with no bureaucratic barriers.
- To ensure that all those who could benefit are made aware of the Personal Assistance Service in order that those who wish to live their lives independently can access the necessary supports to do so

Separate from the legislative process, the NDIS should be tasked with providing the necessary cross-departmental discussion on the value of the PAS and how a support system for promoting Inclusion can be embedded within the work of the remainder of the strategy.

Living in the Community: People with disabilities are supported to live an independent life in a home of their choosing in the community

There seems to be a clear driver for the National Housing Strategy for Disabled People 2011 to 2016. ILMI Analysis shows a lack of real consistency in the approach to developing local plans. NDIS in conjunction with the Housing Agency and the Department of Housing need to design a template that can assess housing needs and monitor implementation. NDIS needs to deliver a strong message that Capital investment in social housing delivered by Local Authorities is essential to deliver accessible housing for disabled people.

7. If you had the opportunity to include one additional action for the 2020-2021 strategy what would that be?

NDIS to resource a process for supporting real engagement and participation of authentic disabled people's voices in all consultative processes with Statutory Processes.

At its very core, the NDIS is about inclusion. For ILMI, our philosophy can be summed up as "Nothing about us without us". For too long, disabled people's lives were decided by others. While there has been progress in this area from the Consultative Committees set up under Section 31 (2) of the Disability Act 2005, there is still work to be done.

NDIS has a number of actions which make commitments to participation for example, in Strategy Item 2 ("Joined up Policies and public services"), specifically action 32 ("Departments and agencies will actively engage people with disabilities through consultative committees and / or other appropriate fora") and action 33 ("We will embed a culture and process of early engagement with people with disabilities in mainstream service

design and evaluation”) and strategy Item 6 (“Person-centred Disability Services”) specifically action 89 (“The National Disability Stakeholders Group, which includes a number of individuals appointed in their own personal capacity to bring their lived experience to the table, will continue to have a central role in monitoring the implementation of the NDIS”).

Challenges of Representation:

While there have been long-standing commitments from Statutory bodies to ensure people effected by decisions are partners in policy development, in practice certain challenges, not specific to engaging disabled people, exist and need to be addressed, namely:

- Community representatives may lack the time to their role. Almost all the other representatives present are there in a paid capacity (Statutory and NGO), and those in paid positions usually devote most of their professional time to being immersed in the policy and legislative context of which the discussions take place. Community representatives are often asked to read and analyse large volumes of policy in their spare time with little (or no) supports.
- There are no specific structures invested in to support authentic voices. While people may come forward to represent a group or community, without a way for that community to have a role in supporting that representative, it simply means an individual is at the table and not the community.
- There is a lack of shared understanding of what the policy forums are and whether community representatives have any power, or whether their participation is at the behest of agencies.

Specific to disability policy spaces, additional barriers may exist:

- Many professionals operate from a medical model of disability, and there is often little or no time and space to explore whether people working together to develop policy have a shared understanding of disability equality.
- Frustration at lack of change in people’s lives can impact on representatives, including challenges from community about their inability to affect change.
- Access and inclusion are often not embedded into the practice of committees and structures. This includes supports such as ISL, a PAS, accessible materials in advance of and during meetings along with consultation with disabled people about locations of buildings with accessible transport and timing of meetings that work for disabled people and not just for professionals.

ILMI’s role as a representative DPO

ILMI as a national representative Disabled Person's Organisation (DPO) has developed a strategic plan (<https://ilmi.ie/wp-content/uploads/2018/09/ILMI-Strategic-Plan-2019-2022.pdf>) where one of the core objectives is Leadership and Representation, where our work will continue to be led and represented by disabled people at all levels. To do this, ILMI creates structures to generate evidence-based policies and expertise based on lived experience.

To do this, ILMI create structures at a regional and national level for ILMI members to engage in dynamic and creative spaces to generate collective policies to represent the organisation. We promote active membership engagement in ILMI spaces through face to face group meetings and the use of technology (specifically video conferencing) to support virtual real time and non-real time participation. We share ILMI policy processes to ensure collective ownership and provide training and supports to build the capacity of ILMI representatives.

We work to ensure that those in leadership roles are supported by members through peer support to be authentic voices by creating structures to generate policy discussions, and linked with this we create ways for those in leadership roles to provide feedback on ILMI's representation work locally, nationally and internationally. As a DPO, all ILMI representatives work to increase the visibility of disabled people in discussions on equality and social justice locally, nationally and internationally.

ILMI defines real participative representation of disabled people as being based on the principle that individuals bringing collective views / strategies together in defined ILMI spaces to influence policy and service delivery.

Central to how we work is the effective involvement of people with lived experience: "Nothing about us without us". From the individual we work to develop collective expertise of ILMI members which reflect diversity of experience, based terms of gender, sexuality, ethnicity, age, marital status, socio-economic status and impairment and working on building a consensus approach to define ILMI's position.

This approach, with support from ILMI staff, works to move from "users" of services to "makers and shapers" of policy. The collective policy developed is based on the assumption that ILMI's policies will positively change society for all rather than advocate for individual needs. ILMI's processes are about embedding and the deepening of democratic participation by ensuring disabled people have their collective voices heard.

Spaces are openly and transparently announced via social media and our biweekly eBulletin. Rather than solely use face to face meetings, ILMI recognises that there may be many barriers to participation: lack of PA hours, accessible transport, time commitments due to family or employment etc. On that basis we use video conferencing to facilitate participation, using a free app called Zoom, which allows us to host virtual meetings with up

to 100 participants. In parallel we still hold direct face to face workshops on specific policy developments or training (such as Leader training, lobbying, representation etc.).

ILMI members not only identify issues, but within these spaces identify the strategic priorities and possibilities within the existing policy context, so that representatives have an authentic mandate to prioritise approaches and work to co-create and work alongside civil and public servants to bring around change to achieve our strategic objectives and build an inclusive society. Central to this approach is that all representatives' feedback is key information from local and national discussions spaces to that ILMI as a collective can be part of this work. This allows for full transparency, not only in an attempt to hold policy to account, but in terms of transparency in how ILMI operates and where policy is discussed and developed.

Presently, as per our strategic objectives, ILMI has working groups which discuss, develop and support representatives locally and nationally on education, employment, housing, planning, transport and personal assistance services. We also facilitate discussions on emerging issues as well as spaces to discuss how to work collectively.

UNCRPD and the role of a DPO

The UNCRPD makes specific references to State party commitments to ensure disabled people are effectively involved in all policy forums.

Article 4 – General obligations

3. 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, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Article 29 – Participation in political and public life

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake:

b) 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:

i. 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;

ii. Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

The definition and role of a DPO is expanded in General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (<http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhsnbHatvuFkZ%2Bt93Y3D%2Baa2pjFYzWLBu0vA%2BBBr7QovZhbuyqzjDN0plweYI46WxrJJ6aB3Mx4y%2FspT%2BQrY5K2mKse5zjo%2BfvBDVu%2B42R9iK1p>):

“The Committee considers that organizations of persons with disabilities should be rooted, committed to and fully respect the principles and rights recognized in the Convention. They can only be those that are led, directed and governed by persons with disabilities. A clear majority of their membership should be recruited among persons with disabilities themselves. Organizations of women with disabilities, children with disabilities and persons living with HIV/AIDS are organizations of persons with disabilities under the Convention. Organizations of persons with disabilities have certain characteristic aspects, including the fact that:

(a) They are established predominantly with the aim of collectively acting, expressing, promoting, pursuing and/or defending the rights of persons with disabilities and should be generally recognized as such;

(b) They employ, are represented by, entrust or specifically nominate/appoint persons with disabilities themselves;

(c) They are not affiliated, in the majority of cases, to any political party and are independent from public authorities and any other non-governmental organizations of which they might be part/members of;

(d) They may represent one or more constituencies based on actual or perceived impairment or can be open to membership of all persons with disabilities;

(e) They represent groups of persons with disabilities reflecting the diversity of their backgrounds (in terms of, for example, sex, gender, race, age, or migrant or refugee status). They can include constituencies based on transversal identities (for example, children, women or indigenous people with disabilities) and comprise members with various impairments;

(f) They can be local, national, regional or international in scope;

(g) They can operate as individual organizations, coalitions or cross-disability or umbrella organizations of persons with disabilities, seeking to provide a collaborative and coordinated voice for persons with disabilities in their interactions with, among others, public authorities, international organizations and private entities.”

At present, there are clear commitments to supporting disabled people to be involved in Statutory policy development, from the Disability Act to the HSE's Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places (published September 2018)³, Housing and Disability Steering Groups operated by Local Authorities as well as the Local Government Reform Act (2014) which gives scope for disabled people to participate in local PPNs.

What is currently lacking is a commitment to resource and explore how disabled people can be effectively supported to bring authentic voices to consultative spaces. ILMI presents a model, using technology and led by a DPO whereby disabled people can support representatives to bring forward positions and approaches that can bring change about at a bilateral or broader committee level.

³³ <https://www.hse.ie/eng/services/publications/effective-participation-in-decision-making-final.pdf>