



INDEPENDENT LIVING
MOVEMENT IRELAND
FREEDOM • RIGHTS • EMPOWERMENT

www.ilmie.ie

**(Image shows ILMI logo with Text: Independent Living Movement Ireland.
Freedom, rights, empowerment and website address www.ilmie.ie)**
Observations on HDSGs for the Housing Agency

June 2022

Introduction to Independent Living Movement Ireland

Independent Living Movement Ireland (ILMI) is a campaigning, national Disabled Person's Organisation (DPO) that promotes the philosophy of independent living and seeks to build an inclusive society. ILMI works with disabled people on a cross-impairment basis. Central to the way we work is to ensure that policy and legislative discourse and 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.

Social model of disability

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 there is a clear and full understanding of what the social model of disability is and how it should

inform future discussions on policy development and improvement and policy implementation.

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.

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, people experiencing emotional distress and physical and sensory impairments.

ILMI welcomes the call for people with lived experience onto the Housing Disability Steering Groups (HDSGs) as part of the new housing strategy for Disabled people 2022-2027. From our own research and engaging with our members it is very clear many disabled people are interested in becoming involved in decision making structures about their lives such as the HDSGs. Additionally, there are specific commitments under the UNCRPD about the need for the active involvement of disabled people through their representative organisations (DPOs) to be actively involved in the design, delivery and monitoring of policies, procedures and structures that directly impact on our lives.

As a DPO we consulted our members on participating in the HDSGs and they identified the need for training in order to take up representational roles. ILMI ran a series of online programmes such as “Making Inclusion a Reality” and a “Housing Network” to prepare Disabled people and to build their capacity to enable them to contribute and participate effectively on their HDSGs and other local decision making structures.

We also recognise that in the previous housing strategy for disabled people, there was an absence of investment in supporting disabled people to participate in HDSGs. Until recently, there has been an absence of autonomous collective spaces for disabled people to nominate representatives onto policy spaces such as the HDSGs. Therefore, the active involvement of disabled people bringing collective issues from an equality and human rights perspective informed by the social model is going to require training for all members of HDSGs, including elected representatives, Local Authority staff and other agencies. In order for HDSGs to be genuinely inclusive, there needs to be an investment in training supports to ensure all members of the HDSG have a shared understanding of the social model of disability and how inclusive housing can remove one of the disabling societal barriers which prevents the active participation of disabled people. This training needs to be developed by DPOs in conjunction with the Housing Agency.

Making Inclusion A Reality

Funded through the Irish Human Rights Equality Commission (IHREC) Equality and Human Rights and Equality Grant scheme, “Making Inclusion a reality” is an ILMI initiative in partnership with South Dublin County Council. The aim of the project was to develop best practice on the inclusion of disabled people on a HDSG. The project was about facilitating disabled people to work collectively to inform the development of housing policy to inform the South Dublin County Council HDSG.

The project was also about establishing models of best practice for public bodies in how to engage with disabled people in the design, delivery, implementation and monitoring of policies that impact on our lives, including the public sector duty. It is

really important that all policy that affects disabled people should be made in direct consultation and engagement with us involved.

Some results of Making Inclusion a Reality were:

- The establishment of a network of disabled people with different impairments across the South Dublin County council area.
- It had a values led approach and included ILMI values of freedom, choice, control and empowerment.
- It built the confidence of disabled people to represent the views of all disabled people in their area effectively.
- As a direct result of [“Making Inclusion A reality”](#) ILMI has two active reps on South Dublin HDSG and our report on this “model of best practice” is available on our website on www.ilmi.ie (hyperlinked above)

The ILMI housing network:

During the development of the new National strategy for housing disabled people a number of local authorities were reviewing their membership of their HDSGs and welcomed the contribution and expertise of the voice of lived experience of disabled people.

Listening to our membership ILMI developed a training programme and a series of presentations of inputs which allowed people who are interested in becoming ILMI representatives on the HDSGs to be informed when nominated onto their HDSGs and attending meetings.

Some of the topics covered were:

- Having our Voices heard: Representation and Participation.
- A Home Not an Institution; Rights Not Charity.
- Housing as a human right and designing for diversity.

- Networking and building Allies.
- The importance of negotiation and dealing with conflict.

After these two programmes concluded ILMI gathered as a collective of disabled people to share the authentic lived experience of what it is like to be a part of these HDSG structures. We identified by being invited to be a part of the HDSG structure disabled people feel a sense of empowerment and fulfilment to be a part of meaningful change for disabled people. We know that a lot of HDSGs are welcoming disabled people onto their local structures. This is a positive development, given that in previous [ILMI research](#) it was not clear how many disabled people were on HDSGs as part of the old housing strategy for people with disabilities 2011-2021.

ILMI recommendations for HDSGs to continue to be effective:

Need for Disability equality training

- We feel Disability equality training needs to be a fundamental requirement for all HDSG members to attend in order to fulfil their role on the HDSG. This would allow HDSG members to begin to view housing for disabled people through a rights-based approach.
- Disability Equality training needs to be promoted by the Housing Agency and delivered by DPOs. This needs to embed consistent social model analysis of disability into all HDSGs. The social model of disability and a human rights approach needs to be at the core to align with the UNCRPD
- Disability Equality training needs to establish clear values for the role of HDSGs and commitments to the inclusion and active participation of disabled people and the specific role of DPOs as the authentic collective voices of disabled people. This training would build peoples knowledge of the difference of DPOs versus “disability organisations” or “service providers”

Need for Disabled people to be paid for their time (including expenses)

- Members felt that disabled people have the expertise of lived experience and thus their experience, expertise and time should be valued. This will make

sure disabled peoples inputs are valued and that “we are not just the token disabled person” around the table.

- In order for a disabled person to fulfil their role and contribute effectively, provision should be made to provide adequate support such as PA support, ISL, taxis to and from the venue etc. as outlined under public sector duty.

Need for effective communication

- We feel there should be effective and structured guidelines to how HDSGs are conducted or that this is formally in TORs or as a code of practice to ensure respect is upheld for everyone attending. Without a defined structure disabled people often feel “the meeting can be a “tick box exercise” in some cases leading to the same issues be brought up time and time again with no progression. With this in place this would avoid anyone feeling disrespected
- Another point noted was the importance of having a designated Point of contact for the HDSG to use if any member of the HDSG has any queries or needs support. Our pilot programme “Making Inclusion a Reality” highlighted how effective this was in establishing a link and understanding of the HDSG and its role to disabled people taking on representative roles on HDSGs. This would include an introductory pre-meeting to give an update on the work of the HDSG, its role and its values.
- ILMI recommends that all meeting agendas and materials need to be circulated at least a week in advance of the meeting (this includes consultation briefing notes etc.). This is for accessibility purposes but also allows all HDSG members the adequate time to review and contribute to the agenda effectively.

Need to change language as per new National Housing Strategy:

- ILMI recommends that all HDSGs change their language to be in line with the new National Housing strategy. Some reps reported that some HDSGs are reluctant to change the language until the housing agency direct them to do so.

