



Disabled People and the Programme for Government

Independent Living Movement Ireland submission in relation to the development of a Programme for Government based on promoting inclusion of disabled people as equals in Society

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 that need to be addressed in the development of a Programme for Government that genuinely puts the needs of disabled people at the centre of policy development and works towards the inclusion of disabled people as equals in Irish society.

Context:

ILMI notes the draft document between Fianna Fáil and Fine Gael to facilitate negotiations with other parties on a plan to recover, rebuild and renew Ireland after the COVID-19 emergency. We note with interest “the importance of the well-resourced, properly functioning and responsive State has never been clearer” which resonates with disabled people’s views on the need for Statutory supports to build inclusion.

We note the commitment to achieving “a stronger, more inclusive Ireland” and notwithstanding our concern at the use of the term “special needs” we welcome the commitment to a new social contract to “empower all people with special needs or a disability to progress, to reach their full potential, and to play a full part in society” as a real commitment to an inclusive Ireland.

We welcome the commitment to “enable young people with disabilities or special needs to live as independently a life as possible”; however we feel the right to independent living for disabled people should not be based on age.

Our Members have identified the following crucial elements of developing a Programme for Government that will build an inclusive Ireland that really can empower disabled people to their full potential to live independent lives.

1. Ensure that all decisions in relation to disabled people's lives are made in direct consultation with Disabled People.

“Nothing about us without us”: For far too long, decisions and supports framed for us around our disabilities in all aspects of our lives are decided by others. Ireland has ratified the UNCRPD, and there are specific articles (4.3 and 29b) that relate to the role of Disabled Person’s Organisations (DPOs). These are separate from disability service provider organisations as DPOs are led by Disabled People and this forum is where we need to have our contributions heard and recognised in policy development.

“Funding is the true recognition of commitment”: For true recognition and support of the independence of DPOs in our campaigning work, a new funding stream, at a remove to the Health Service Executive (HSE) should be advanced by government via the Department of Justice and Equality, keeping DPOs close in our working relationship to the development of equality and human rights policy. A funding stream resourced through the Department of Justice and Equality would begin to remove the fetters of the “medical model of disability”. DPOs need to be permitted to speak freely about aspects of the medical model of disability which also imprisons us in a charity continuum of pity perpetuated by service providing organisations, and inadvertently endorsed by the HSE.

This very much is in parallel with commitments in the Fianna Fail / Fine Gael document to “support community groups, arts and cultural bodies, sports clubs, voluntary organisations, charity groups and voluntary bodies to recover and grow in the aftermath of the COVID-19 Emergency”. These groups must be truly representative and based on principles of participative democracy in order to bring forward authentic voices of their communities.

We want the Programme for Government to explicitly commit to direct engagement with Disabled Person’s Organisations and ensure that they are resourced so that we can engage effectively in policy development.

2. Legislate for a Right to Personal Assistance.

The Personal Assistance Service (PAS) is a tool that allows us to live independently. The PAS 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 chose. 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 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 PAS 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 PAS is often the difference between existing and living for many of us.

The right to a Personal Assistance Service is central to the aims outlined in the Fianna Fail / Fine Gael draft document to “empower all people with special needs or a disability to progress, to reach their full potential, and to play a full part in society” and to “enable young people with disabilities or special needs to live as independently a life as possible”.

We want the Programme for Government to commit to introduce legislation to guarantee us the right to a Personal Assistance Service as per Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

3. Ensure commitment to Personalised Budgets for disabled people during lifetime of new Government

The publication of “Towards Personalised Budgets for People with a Disability in Ireland Report of the Task Force on Personalised Budgets” and the development of a demonstration model was a welcome commitment in the last programme for Government. This demonstration model process needs to be resourced and from this any learning to be processed and adopted as policy to ensure disabled people can access direct payments from 2021.

We want the Programme for Government to continue to commit to ensuring the Personalised Budgets demonstration models are rolled out and learning from these to ensure direct payments become a reality for disabled people who want them over the lifetime of this new Government.

4. Commit to Investment in accessible Public Housing.

Ireland is currently in the midst of a housing crisis, but there always has been a crisis for disabled people due to the lack of accessible housing. We 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. We are also particularly over-represented in the homeless population: more than one in four homeless people are disabled.

There are concerns about the disabled people who are the “hidden homeless” where disabled people who live in other people’s homes and who are not on any housing list or where there is no expectation that they should live independent lives. There are also thousands of disabled people in residential and congregated settings who are denied a right to their own home, and lack of delivery of policy in terms of housing means that their needs are not being met.

Reliance on the Private Sector will not work and does not work for us, due to our particular accommodation needs and therefore many of us require investment in Public Housing.

Noting that part of the Mission of the draft Fianna Fail / Fine Gael document is “Housing for All”, it is disappointing that no specific reference is made to the number of public housing to be made accessible for disabled people.

We want the Programme for Government to commit a minimum of 10% of all social housing in their election manifestos and the development of any future programme for Government.

5. Commit to fulling resourcing and implementing A Time to Move On and end inappropriate institutional life

The HSE policy “Time to Move on from Congregated Settings: A Strategy for Community Inclusion” (2011). Its aim was to ensure that “people living in congregated settings will move to dispersed forms of housing in ordinary communities, provided mainly by housing authorities.” The report highlights in detail how institutional life robs disabled people of the independence to control their own lives and recognises that institutional life which results in “lives lived without dignity”.

Yet, nine years on, thousands of disabled people continue to live in effective incarceration without the right to choose where they live in institutions.

There are also over 1000 disabled people inappropriately placed in nursing homes for the over 65s due to lack of appropriate supports such as personal assistance services or accessible housing.

The Covid19 outbreak has shown once again how inappropriate institutional life is. Not only does it deny people of agency and dignity in controlling where or who they live with, it also places disabled people and other groups inappropriately placed in institutions such as people seeking asylum in direct provision in unsafe, unhealthy environments.

We want the Programme for Government to resourcing through the right to a PAS and inclusive public housing to ensuring the full implementation of a Time to Move On over the lifetime of Government. The Programme for Government also needs to align this policy with ending the system of Direct Provision.

6. 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

ILMI welcomes the commitment in the Fianna Fail / Fine Gael draft document to develop a new social contract based on “principles of equality and ensuring that every citizen has the opportunity to contribute to, and achieve, their potential.” The Covid19 crisis has demonstrated that connection to other people is vital to ensuring our wellbeing.

Social distancing practices showed the need for investment in technology and supports to reduce social isolation. Welcoming the commitment to rolling out the National Broadband Strategy, ILMI knows from experience the potential for technology to connect but that our experience in how supports are needed to ensure that disabled people are actively targeted to avail of internet connectivity.

ILMI as a DPO is leading at a national level innovative approaches to ensuring disabled people remain connected using technology. During the Covid19 pandemic we ramped up our online communities to meet our members' needs, developing new and exciting ways for disabled people to connect as peers. We established online art classes, creative writing workshops, photography classes, Yoga and exercise classes, emotional wellbeing courses, a film club, Peer support spaces for disabled people in counties Donegal, Sligo, Leitrim, Cavan, Monaghan, Galway and Clare as well as a national space to discuss issues relating to Covid19 and the Personal Assistance Service. We also developed online discussion spaces to empower members to take on representative roles locally and nationally. All of this was achieved by ensuring our values as a DPO meant that we explored technology that ensuring disabled were supported to use Zoom as an interactive video conferencing system, based on work carried out by ILMI in the previous eighteen months.

ILMI is also delivering an innovative cross border project called ONSIDE which is active in reducing isolation for disabled people in the border counties. We do this by mapping local services, mainstream opportunities and educational options for disabled people living specifically in the counties of Donegal, Sligo, Leitrim, Cavan, Monaghan and Louth. The ILMI mapping of local services, and opportunities, gives the disabled participants the options and information, to follow their chosen life paths. They are facilitated in this by individual, tailored, support from social model-led Community Navigators and other ILMI staff.

The ONSIDE initiative facilitates disabled people to embrace affirmative roles as active citizens in their local communities and has the added benefit of creating more diverse communities. It has a positive, and sustainable impact upon local communities, for both disabled people and non-disabled people, and builds a truly more inclusive society based on equality and participation as committed to in the draft Fianna Fail and Fine Gael document. Public amenities, whether social, cultural, sporting or educational benefit from a larger participation of disabled people and actively builds a more inclusive Ireland.

We want the Programme for Government to commit to building on the experience of ILMI to effectively resource social inclusion through the provision of digital training for disabled people as an effective way to reduce isolation and build inclusive online spaces as pioneered by ILMI in all our work and our innovative ONSIDE project to include disabled people across the country.