



ILMI

INDEPENDENT LIVING
MOVEMENT IRELAND

**ANNUAL
REPORT
2019**

Nothing about
us without us

Our Vision

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.

Mission

We are working collectively to create an Independent Living Movement in Ireland which is led by disabled people and promotes a rights-based social model of disability, challenging the unacceptable charity / medical model of disability. We are working towards the removal of societal barriers that prevent active equal participation of disabled people, challenging the denial of people's rights and the promotion of the philosophy of independent living.

Core Values

Our core values are underpinned by the philosophy of Independent Living and all activities are aimed towards promoting: Independence, Options, Rights, Empowerment.



Our Principles

We promote the active participation of leaders in all aspects of the work of ILMI: locally, regionally, nationally and internationally.

We are a DPO (disabled persons organisation) formed to ensure that the voice of disabled people will be heard in campaigns, research and policy development.

We recognise and promote equality within our members, in terms of gender, sexuality, ethnicity, age, marital status, socio-economic status and impairment.

We will actively promote an understanding of disability as an interaction between a person's impairment and the societal and environmental barriers that disable people's participation in society – and actively lobby to remove these barriers to participation and challenge the unacceptable medical / charity model of disability.

We are committed that ILMI continue to develop new innovative models to achieve equality of outcome, recognising that people have a variety of abilities, needs and wants.



Chairperson's Review

It gives me much pleasure, as chairperson of ILMI, to open the introduction to our 2019 report. It has been an extremely busy year as you will learn from reading the pages which follow. The quality of our work and the reach of the many programmes and tasks is due to the hard work of our staff members, the direction of our CEO, and the time given by the board in support of our mission and the work programme for 2019.

I assumed the chair in November following on from our annual general meeting and conference which was acclaimed as a successful gathering of ILMI members, present in the Gibson Hotel or joining us via Zoom video link. That meeting was not only a sign-off on our work for 2019 but, for me, the enthusiasm and energy surrounding that assembly was a foretaste of the hunger of our members for the board to accelerate driving the status and standing of ILMI into the indisputable status of DPO.

What I took from the energy in our AGM and conference was for us to take the values of our independent living movement to other disability groupings to show them how much had been achieved by this great movement since 1992, and how it still had an energy to do more and had a generosity to invite others to share in that work of making an inclusive society for all disabled people.

Des Kenny, ILMI Chair

Chief Executive's Review

2019 was another very successful year for us as Movement. Over the course of 2019, we use Zoom and face to face discussion spaces to ensure direct involvement of disabled people in discussions to develop ILMI policy positions on Housing, Transport, Education, Personal Assistance, Activism and representation structures, Planning, Representation of Disabled People in the Media and Deinstitutionalisation.

We have continued to work with disabled activists in Galway through the Galway Activism Group and Clare through the Clare Leader Forum to ensure disability equality discussions locally are led by disabled people on local structures.

ILMI representatives worked on committees with ICTU, IHREC, the Comprehensive Employment Strategy, the Oireachtas Disability Group, Taxi Advisory Committee, Community Platform, the European Anti-Poverty Network (EAPN), the Coalition Against Hate Crime, the Love Not Hate Campaign, All Together in Dignity (ATD) Ireland. ILMI worked with European Network on Independent Living (ENIL) on "The Present and Future of Personal Assistance in Europe" and the Freedom Drive 2019. We also made a number of submissions over the course of 2019 including to the National Disability Inclusion Strategy mid-term review and to the Oireachtas Committee on Housing among others.

We represented the organisation at events organised by the Ombudsman for Children's Office, the Disability/Visibility Conference National University Ireland Galway (NUIG), the HSE National Disability Services Sharing Day, the Economic and Social Research Institute (ESRI), Social Care Ireland, the European Disability Forum (EDF), HSE discussions on Personalised Budgets and EY's Diversity and Inclusion In-Motion Summit.

In May this year, we finally started our ONSIDE project. ONSIDE is a cross border project led by Independent Living Movement Ireland (ILMI), Disability Action Northern Ireland; Supporting Communities and the Northern Ireland Housing Executive. The goals of ONSIDE is to reduce isolation in the border counties and create possibilities for enhanced mental and physical health with their chosen communities.

ILMI ONSIDE will achieve 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. In just six months, the ILMI ONSIDE staff team have achieved a huge amount of work and set a platform for much more in the years to come.

We launched our Declaration of Independence video campaign to increase awareness of disability rights was launched on European Independent Living Day 5th of May 2019 #ILDDay19. In June we launched our Leader Manual developed by leaders for leaders as the definitive guide on running a Personal Assistance Service.

Over the course of 2019, we developed our #PASNOW campaign, building relationships with politicians across all parties. In June we launched "Achieving a Right to Personal Assistance in Ireland" which was a collaboration between the Centre for Disability Law and Policy at NUI Galway and ILMI. The paper was launched by Minister Finian McGrath in the Oireachtas and the event was hosted by Senator Colette Kelleher.

From this launch ILMI worked with Eversheds Sutherland, who developed a Private Members Bill on a pro-bono basis the Public Interest Litigation Association (PILA) and worked with Deputy Thomas Pringle TD to bring a Bill into the Dáil in November. Due to changes in Dáil standing orders, we could only bring a motion which was successfully passed on November 19th. This was achieved by ILMI members actively lobbying their local TDs leading to an informed debate in the Dáil about disabled people's rights, inclusion and independent living. From this, we have begun working with disability activists to get Local Authorities across the country to have motions passed at City and County Council level to support the right to a Personal Assistance Service- and will continue to do so in 2020.

I want to use this opportunity to recognise to thank everyone who has participated and contributed to the work of the organisation at every level. I especially want to acknowledge the work that the board has put in over the course over the year.

I want to recognise the support of that Shelly Gaynor gave as chair until her resignation from the board in November this year. I would like to also recognise the support given by our new chair Des Kenny in the last two busy months and look forward to working with him over the next years ahead.

I would like to thank Selina Bonnie, Audrey Brodigan, Sarah Fitzgerald (Secretary), Dermot Hayes (Vice Chair), Des Kenny (ILMI Chairperson), Marian Maloney, Sinead Murtagh, Michael Nestor, Dr John Roche, Gordon Ryan (Treasurer) for their commitment to the organisation and the work they have put which means that the organisation is managed to the highest standards.

It was with great pleasure that the ILMI staff expanded over the course of 2019 with the addition of six new positions through the ONSIDE programme which added new energy and expanded the reach of ILMI as an organisation.

I want to acknowledge the work of the staff team: Orla Beirne, Susan O'Brien, Nina Byrne, Dr James Casey, James Cawley, Angela Coleman, Marie Gilligan, Edel McGinley, Peter Kearns and Maryam Madani for their dedication, expertise and passion they bring to their roles and their work as a team.

I want to thank those who gave their time to the organisation as volunteers over the year to ILMI: Grace Murphy, Molly Lavin, Kitty Fong and Maria Mann.

And finally, but most importantly, I want to acknowledge the huge contribution made by members across the country, who have given their knowledge and expertise to be part of a Movement for change, through participation in meetings locally and nationally or via zoom, participating in workshops and taking the time to promote the ILMI #PASNOW campaign in November.

Over the course of 2019 we have firmly established ILMI as a national Disabled Person's Organisation with a unique mandate to lobby for disabled people's rights. With a general election looming in early 2020 and Ireland having its first review under the UNCRPD, the potential for ILMI to promote a rights-based approach to disability has never been stronger.

Damien Walshe, ILMI CEO

Strategic Objectives

Strategic Objectives for ILMI 2019 to 2021

Governance, Accountability & Transparency

Leadership & Representation



Promotion of Equality & Accessing Human Rights

Political Campaigning & Strategic Policy Development



Governance, Accountability & Transparency

What we aim to do: We will maintain the highest standards of Governance, accountability and transparency to our members and funders and will develop a funding strategy to secure the sustainability of the organisation.

The ILMI board of management met seven times over the course of 2019 and the following people served as board members over the course of 2019.

Shelly Gaynor (Chair, stepped down from Board November 2019)	
Des Kenny (Chairperson from November 2019)	
Dermot Hayes (Vice Chair from November 2019)	
Michael Nestor (Vice Chair until November 2019)	
Gordon Ryan (Treasurer)	Dermot Hayes
Sarah Fitzgerald (Secretary)	Selina Bonnie
Audrey Brodigan	Sinead Murtagh
John Roche	Marian Maloney

The board of ILMI met 6 times over the course of 2019 and ensure that all matters relating to compliance were met (CRO, Revenue, Charities Regulator, GDPR and Lobbying register).

In order that ILMI is transparent with all its work, we send a biweekly eBulletin to an email mailing list of 400 contacts, which includes all ILMI members. These are also uploaded onto our ILMI website eBulletin section <https://ilmi.ie/ebulletins/>

ILMI uses social media to increase our profile and ensure transparency in our work. By the end of 2019 we had 3,875 total Likes and 3,854 total Follows on our Facebook page. We have 1,119 followers on Twitter at the end of 2019, an increase of 315.



Staff

The following people were employed by ILMI in 2019:

- Orla Beirne ONSIDE Community Navigator (from August 2019)**
- Susan O Brien Development Worker**
- Nina Byrne Communications Officer (maternity leave from October 2019)**
- Dr James Casey ONSIDE health and housing officer (from June 2019)**
- James Cawley Policy Officer**
- Angela Coleman ONSIDE administrator (from June 2019)**
- Marie Gilligan ONSIDE Community Navigator (from August to December 2019)**
- Edel McGinley ONSIDE Community Navigator (from June 2019)**
- Peter Kearns ONSIDE Project coordinator (from June 2019)**
- Maryam Madani ILMI communications intern (from October 2019)**
- Damien Walshe CEO**

Staff meet biweekly to ensure collective coordination of its work. The CEO provides direct support and supervision to all staff on a structured basis every six weeks to ensure accountability of projects within the strategic objectives.



Leadership & Representation

What we aim to do: Independent Living Movement Ireland's work will continue to be led and represented by disabled people at all levels. ILMI will create structures to generate evidence-based policies and expertise based on lived experience.

Part of our strategic objective on leadership and representation is about building a shared understanding about the philosophy of Independent Living. In June we launched our Leader Training Manual which was based on discussions and pilot training carried out in 2018.

(https://ilmi.ie/wp-content/uploads/2019/06/Leader_Manual_June_2019.pdf and MS Word

https://ilmi.ie/wp-content/uploads/2019/06/ILMI_Leader_Manual.docx)

ILMI supported the development of Galway Activism Group and Clare Leader forum. Both local groups held very successful events over the course of 2019, including election hustings for the local elections. Clare Leader Forum also supported activists to complete a course on activism in LIT.

In September we held our AGM and Conference 'Nothing About Us Without Us: What does Representation Mean in Building a Grassroots DPO'. The conference was themed to look at how ILMI developed as a representative disabled person's organisation (DPO) and how we build a collective with shared analysis, approach and a commitment to working together. In order to generate discussion, we were privileged to be joined by ILMI members Elaine Howley, Pdraig Hannafin and Seònaid Ó Murchadha as well as disability activists from the UK Colin Cameron, Maggie Cameron and Ellis Palmer. ILMI ONSIDE health and Housing and officer James Casey was MC for the panel discussion and a lively open mic session. There was huge energy and ideas about how to represent disabled people, disability equality, the importance of language, tokenism, the need for disabled people to work collectively and the need for ILMI to provide strategic focussed campaigns for people to mobilise on.

Prior to the Conference, ILMI had a very successful AGM, which included a strong debate on a developing a declaration to service providers, Statutory bodies and NGOs on what "Nothing About Us Without Us" means.

ILMI built relationships with the following organisations:

ICTU, IHREC, the Comprehensive Employment Strategy, the Oireachtas Disability Group, Taxi Advisory Committee, Community Platform, the European Anti-Poverty Network (EAPN), the Coalition Against Hate Crime, the Love Not Hate Campaign, All Together in Dignity (ATD) Ireland.

Promotion of Equality & Accessing Human Rights

What we aim to do: Independent Living Movement Ireland's work will be grounded in equality and a rights-based approach, working towards an inclusive Irish Society.

In June we were delighted to launch the Outreach and Navigation for Social Inclusion and Digital Engagement project (ONSIDE); a dynamic and exciting creative venture that is co-ordinated by ILMI in the Republic of Ireland and by our partners in Northern Ireland, Disability Action Northern Ireland; Supporting Communities and the Northern Ireland Housing Executive.

From summer 2019 to summer 2022, ILMI will actively work with 375 disabled adults and young people in the counties of Cavan, Leitrim, Sligo, Donegal, Monaghan and Louth who wish to be more effectively involved in their own communities and lifestyle choices. Our vision is to facilitate disability equality led independent living as a feature of border county community choices, not 'special-needs' or 'special-centres' outside of mainstream local participation.

ILMI's ONSIDE Project works by providing one-to-one assistance to disabled participants in the form of free IT equipment and training. We will also organise inclusion workshops to support participants to access mainstream lifestyle choices above and beyond the traditional disability-service provider 'care' options. Additionally, we will organise training and support for project participants to learn how to access and effectively use current web-based technologies. This may involve a free tablet or laptop, with the relevant tailored accessible software for the disabled person to fully use the device to realise their individual lifestyle choices.

ILMI's ONSIDE Project has three border county based Community Navigators who will provide disabled participants with the information and support they require to realise their individual lifestyle choices. Choices that disabled adults' want. This could be anything from an ONSIDE Project participant just wishing to use their IT equipment to pay bills online, or where a disabled person requires information about how to access further education... or even find love. The decisions are the disabled persons' to make.

Declarations of Independence

Our vide Declaration of Independence video campaign to increase awareness of disability rights was launched on European Independent Living Day 5th of May 2019 #ILDay19. Written by ILMI Secretary Sarah Fitzgerald and filmed by Peter Kearns and John Owens, it features twenty disabled activists from across the country delivering a powerful collective message around disability equality.

Political Campaigning & Strategic Policy Development

What we will do: ILMI will empower members to be active agents of social change by participating in collective strategic campaigns to promote independent living and ensure effective policy development and implementation.

ILMI began the process of developing collective policy spaces over the course of 2020 to discuss housing, planning, transport, education and employment, using video technology to ensure members from across the country can be actively involved in all aspects of our work. From this ILMI developed "Principles of Inclusive Planning" which will be distributed to all locally elected politicians, politicians and key stakeholders. Similar policy discussions were developed in Transport, education and employment to work towards ILMI position papers.

The ILMI Housing Group met 5 times over the course of 2019 to collectively highlight the core concerns of disabled people in relation to accessible housing provision. The policy officer analysed the local Housing Disability Plans for all local authorities and developed an submission to Oireachtas Committee on Housing.

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PDF

<https://ilmi.ie/wp-content/uploads/2019/07/ILMI-Submission-to-the-Joint-Oireachtas-Committee-on-Housing-June-2019.pdf>

MS WORD

<https://ilmi.ie/wp-content/uploads/2019/07/ILMI-Submission-to-the-Joint-Oireachtas-Committee-on-Housing-June-2019.docx>

Submissions were also made to the National Disability Inclusion Strategy mid term review.

PDF

<https://ilmi.ie/wp-content/uploads/2019/12/ILMI-Submission-to-NDIS-November-2019.pdf>

MS Word

<https://ilmi.ie/wp-content/uploads/2019/12/ILMI-Submission-to-NDIS-November-2019.docx>

and to Cost of Disability Research.

PDF

<https://ilmi.ie/wp-content/uploads/2019/12/ILMI-submission-to-Cost-of-Disability-Research-October-2019.pdf>

MS Word

<https://ilmi.ie/wp-content/uploads/2019/12/ILMI-submission-to-Cost-of-Disability-Research-October-2019.docx>

#PASNOW CAMPAIGN

The #PASNOW campaign began in March 2018 when ILMI began discussions across the country around what leaders wanted from their PA Services. The key asks of the campaign were to clearly define the PAS; for the State to invest in the PAS to ensure people had the hours they needed; standardise the assessment; promote the PAS among disabled people and legislate to guarantee a right to a PAS as per article 19 of the UNCRPD.

In May we launched “Achieving a Right to Personal Assistance in Ireland”, a collaboration between the Centre for Disability Law and Policy at NUI Galway and ILMI. The paper was launched in the house of the Oireachtas by Minister Finian McGrath in the Oireachtas and a discussion was chaired by Senator Colette Kelleher. The paper was written by Bearnaidín Nic Aogáin, Rory Knight, Mary Melvin, Teopista Nannyanzi, Clíona de Bhailís and Professor Eilionóir Flynn.

This created further awareness of the issue and build more political alliances. At this stage ILMI had offers from two parliamentary parties to explore bringing in legislation as a Private Members Bill (PMB), but Independent TD Thomas Pringle also expressed an interest and given that Independents4Change had a greater likelihood of getting a Bill into the Dail before an election would happen ILMI began the process of working with him.

As a member of the Public Interest Litigation Association (PILA), ILMI applied for pro-bono legal advice to draft legislation for a right to personal assistance. Eoin Mac Aodha of Eversheds Sutherland gave a huge amount of his free time to drafting a bill which was then lodged with the Bills Office in October of this year. This Bill was based on work carried out with CIL / ILMI members back in 2013 and drafted to recognise the PAS as a separate service that needed to be provided for as a social support service within the Department of Social Protection and not within the HSE.

The Bill we worked with Eversheds on was about a right to Personal Assistance for disabled people and it clearly involved proposing to spend exchequer funding. Therefore under SO 179 the Bill, which Thomas Pringle TD was bringing with our support was ruled inadmissible. Deputy Pringle worked with ILMI and the Bills Office to draft a motion which captured the aims of the Bill but which proposed only minimal initial State funding to establish a Commissioner for Independent Living position within the Department of Social Protection and Family Affairs. ILMI members were supported to lobby their TDs across the country and on the 19th November the motion was unanimously passed.

The next stage for that motion is for Deputy Pringle, ILMI and Eversheds to draft specific legislation to enact a Commissioner for Independent Living which can be brought into the Dáil in January which again gives us an opportunity to garner more support.

Nothing about us without us

Independent Living Movement Ireland

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