



INDEPENDENT LIVING
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ILMI eBulletin the 15th of May 2026

Cost Of Disability Summit

The Cost Of Disability Summit marked an important moment in the national discussion on the real costs Disabled People face in everyday life and the urgent need for rights based systems change.

The road to the Summit was built through consultation, discussion and the lived experience of Disabled People across Ireland.

In the lead up to the Summit, ILMI held discussion spaces and consultations with Disabled People on the real costs many of us face every day including transport, housing, energy, healthcare, Personal Assistance, employment and inaccessible systems. These conversations directly informed ILMI's Cost of Disability Position Paper and our contribution to the national discussion. The paper is grounded in collective analysis and practical solutions developed by Disabled People ourselves.

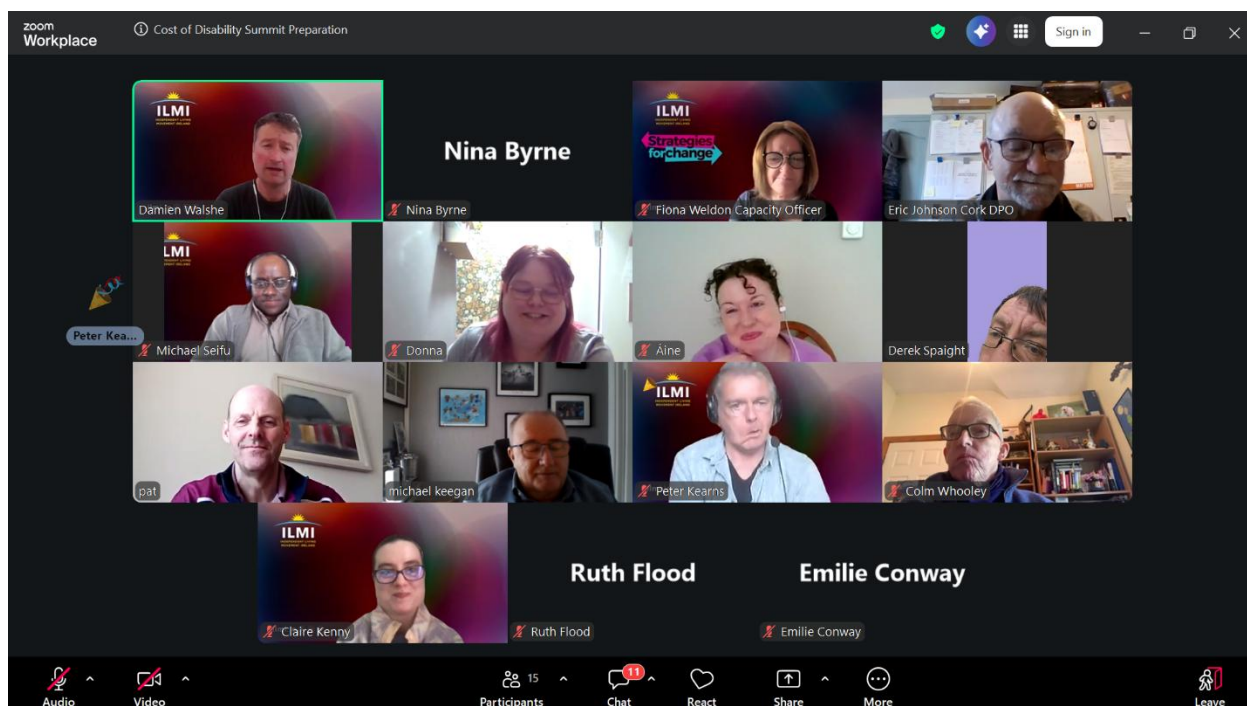


IMAGE: Zoom screenshot of Group

Ahead of the Summit, ILMI also brought together local DPO representatives and delegates from across the country for an online preparation meeting. The discussion was thoughtful, honest and deeply rooted in lived experience, with delegates sharing the real impact the cost of disability is having on everyday life in communities across Ireland. It was a powerful reminder of why Disabled Persons Organisations matter and the importance of collective spaces led by Disabled People.

The Strategic Focus Network Summit on Cost of Disability was organised by the Department of Social Protection as part of the public consultation process on developing a national Cost of Disability scheme. The Summit brought together Disabled Persons Organisations, government departments, civil society organisations and other stakeholders to discuss both a Cost of Disability payment and the wider barriers that create additional costs for Disabled People.

ILMI was represented throughout the Summit by Dr Michael Seifu, Claire Kenny, Fiona Weldon and Peter Kearns, who participated in discussions and table groups focusing on key pillars including education, independent living, employment, transport and wider systems change.

A major highlight of the day was the opening expert panel from the DPO Network, made up of AsIAM, Disabled Women Ireland, Independent Living Movement Ireland, Irish Deaf Society and National Platform of Self Advocates. Representatives brought the voices, experiences and analysis of Disabled People directly into the national conversation on the cost of disability.

The panel featured Brian Hayes, Elaine Grehan, Adrian Carroll, Dr Michael Seifu and Amy Hassett.

A special acknowledgement goes to Dr Michael Seifu, who spoke eloquently and powerfully about the collective work undertaken by ILMI and Disabled People across Ireland on the lived experience of the cost of disability. His contribution reflected the depth of analysis, consultation and grassroots engagement that shaped ILMI's position paper.



IMAGE: The DPO Network representatives left to right, Brian Hayes Chair National Platform of self advocates, Elaine Grehan Advocacy Manager IDS (Irish Deaf Society), Adrian Carroll Senior Policy Officer ASIAM, Dr Michael Seifu Policy Officer ILMI, Amy Hasset DWI (Disabled Women Ireland).

ILMI's analysis is clear. The cost of disability is not simply about income supports. It is about structural barriers, inaccessible systems and the additional costs Disabled People incur in order to participate in society. ILMI continues to call for a whole of government response developed in partnership with Disabled Persons Organisations and grounded in the principles of the UNCRPD and the National Human Rights Strategy for Disabled People 2025 to 2030.



IMAGE: Collage style poster from the Cost of Disability Summit featuring photos of ILMI staff and DPO representatives at the Aviva Stadium during discussions that ranged from education, independent living, employment, transport, housing, healthcare to supports, energy costs, communication and accessibility, and wider systems change. Large typography reads “Cost of Disability Summit” and “Disabled People are the experts in our own lives.”

ILMI’s Cost of Disability Position Paper is grounded in lived experience, collective discussion and rights based analysis from Disabled People across Ireland.

The paper highlights the real costs many of us face every day including transport, housing, energy, healthcare, Personal Assistance, employment and inaccessible systems.

It also sets out practical solutions and calls for co creation with Disabled Persons Organisations.

[PDF and MS Word versions](#) on this link

Nothing about us without us.

COST OF DISABILITY

**Disabled People are
the experts in our
own lives.**



IMAGE: Bold graphic poster with a dark teal background and large white typography reading “Cost of Disability”. Smaller text reads “Disabled People are the experts in our own lives.” The ILMI logo appears in the bottom right corner.

Disability Show 2026



IMAGE: Photo shows Avril Greehan, Pippa Black and Fiona Weldon on stage

The Curragh Racecourse was buzzing recently because so many people gathered for the Disability Show 2026, a event bringing together Disabled People, families, organisations, advocates, service providers and community groups from across Ireland.

One of the standout moments of the day was a powerful discussion featuring three absolute powerhouses Avril Greehan, Pippa Black and Fiona Weldon.

Together they spoke passionately about why Disabled Persons Organisations matter, the importance of Disabled People leading our own movements and policy discussions, and the power of collective action rooted in lived experience.

The discussion highlighted that DPOs are not service providers. DPOs are organisations led and controlled by Disabled People ourselves. They create spaces where Disabled People come together to identify barriers, build shared analysis, influence policy and fight for systems change based on human rights and equality.

A very special shout out to Avril Grehan, who chaired the stage discussion and invited Pippa Black and Fiona Weldon to join her for a fantastic conversation on DPOs and collective action. Avril brought warmth, energy and real skill to the discussion, guiding the conversation like a seasoned talk show host and creating a space that was engaging, thoughtful and full of humour.

There was huge engagement from the audience and a strong sense throughout the day that Disabled People's voices, expertise and leadership must remain at the centre of conversations about disability, accessibility and inclusion.

Give to Gain

Reminder: not to be missed.

ILMI's Disabled Women's Healthcare Working Group Masterclass Series continues on the 20th of May at 6.30pm with Lucy Webster.

Lucy Webster is a journalist, author and disability advocate. Her work focuses on ableism, representation and the lived experience of disabled women, and she is the author of "The View From Down Here".

Real experiences. Real barriers. Real change.

Email fionaweldon@ilmi.ie for your Zoom link.

GIVE TO GAIN

HAVE YOU REGISTERED?

DON'T MISS THIS

ILMI'S DISABLED WOMEN'S HEALTHCARE WORKING GROUP MASTERCLASS SERIES

SESSION THREE WITH

LUCY WEBSTER

Lucy Webster is a journalist, author and disability advocate. Her work focusses on ableism, representation and the lived experience of disabled women, and she is the author of *The View From Down Here*.



20TH MAY AT 6:30PM



EMAIL fionaweldon@ilmi.ie
FOR THE ZOOM LINK



DON'T MISS THIS MASTERCLASS!



REAL EXPERIENCES.
REAL BARRIERS.
REAL CHANGE.



NO WOMAN
LEFT BEHIND.



NOTHING ABOUT US
WITHOUT US.

IMAGE: Bold blue and orange poster for ILMI's Disabled Women's Healthcare Working Group Masterclass Series "Give to Gain" featuring Session Three with Lucy Webster on the 20th of May at 6.30pm. The poster includes registration details and the ILMI logo in the bottom right corner.

This looks like a fantastic opportunity for Disabled writers and creatives interested in film and television.

Screen Stories: Getting Disabled Writers in the Room 2026 is now open for applications.

Click here for [full details National Talent Academy Film & TV](#)

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