



INDEPENDENT LIVING
MOVEMENT IRELAND
FREEDOM • RIGHTS • EMPOWERMENT

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(Image shows ILMI logo with Text: Independent Living Movement Ireland. Freedom, rights, empowerment and website address www.ilmi.ie)

ILMI Presentation to the Joint Committee on Disability Matters and the Joint Committee on Autism discussion on ‘Accessibility in the built environment, information and communication’

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Presented by: Des Kenny (ILMI Chairperson) and Catherine Gallagher (ILMI Board member)

My name is Des Kenny, and I am chairperson of Independent Living Movement Ireland. We are a national cross-impairment Disabled Person’s Organization (DPO) and our vision is an Ireland where we as disabled people have freedom, choice and control over all aspects of our lives and can fully participate in an inclusive society as equals.

As a blind person, I rely on my ears, my hands and my feet, yes, my feet, to give me clues to and replacements for what might usually be perceived as seeing.

At the edges of steps, you will notice a dimpled surface: this is to tell me that I am confronting steps either going up or going down. You will see the same dimpled surfaces at pedestrian crossings and along the edge of platforms in stations to demark the line beyond which it is not safe to venture.

Audio crossings are present in all of our cities and most of our towns, telling me when it is safe to cross the road. They have been growing in numbers from the mid-seventies.

Announcements on our public transport fleets, buses and trains help identify where I might be at any given time, which is when the announcements are working, which can't always be guaranteed.

New audio supports moving into use are Audio Description on films and 10% of our home-produced programmes are targeted to be produced with AD built-in. AD tells me what the scene is comprised of and what the people are doing by way of crying, frowning or looking into the distance when all of these actions contribute to enlargement of the content on screen. Anticipating what you might be wondering: An audio clip from *Pretty Woman* advised me when the couple had gone to bed that "the bed clothes are moving!" Much of the movie stock on Sky Digital contains audio description which can be switched on and off as required. Even the remote controls can be told where to navigate the channel selections to, with the selections talking back to me.

An EU regulation now requires that all new EVs from the summer of this year, should emit an electronic sound when they are travelling below 20km per hour. Travelling in excess of 20KM Beyond that speed, the sound of the tyres on the road is reckoned to provide enough noise to indicate the presence of an EV to a blind person. That regulation is not yet being enforced in Ireland. The same expectation should apply nowadays here to e-bikes and e-scooters.

Another directive from the EU relates to website accessibility.

This directive relates to the content on official government and local authority websites being accessible to screen reading software, or in the case of a low vision person, must be capable of being magnified. We are well advanced in meeting this directive with the National Disability Authority monitoring and encouraging progress with the directive.

In terms of touch: how many of you have picked up a pack of Panadol or Gaviscon in the supermarket or noticed strange dots on medicine packs you get in your local pharmacy. Those dots come also from a European directive on medicines obliging pharmaceutical companies to print the name of the medicine and its dose on the pack.

All that I have described in brief, is a web of assistance that exists to support me to know or to interrogate my environment or, in the case of medicines, tell me what tablets I hold in my hand.

Publishers of books are obliged nowadays to have available digital copies of their publications which can be shared throughout the world to countries signed up to making print material available to people who are blind or may have dyslexia. Ireland is signed up to this book share protocol since 2016.

When I first started my college education in the early 1970s, texts recorded on to cassettes was the only means of learning, apart from listening to the lectures. When I later took on advancing myself through further education, I could do my courses and obtain my degrees with the Open University using materials in digital form made available to me by my computer which talks to me using screen-reading software.

As the world evolves along and into more digital channels, I am told who is at my front door what my thermostat is reading and my Alexa tells me something I asked it to remind me of.

The Committee can be passive watchers of this evolution, or, from time to time, you can look at failures of our planners to think access when designing our multiple environments which make-up our interface with the world of an inclusive society where all disabled people want to live.

I will now pass to my board colleague, Catherine Gallagher.

Thank you Des. I would like you to think about every milestone in your life: Starting primary school; secondary school; sitting your Junior or Inter Cert Exam; the Leaving Cert; going to college, employment, or further training; moving out of your family home – and so on. Did you face significant barriers in getting the information to hand to see through all of those milestones?

Every decision disabled people make can span across multiple government departments. Further to this, departments and public bodies may attempt to redirect you around in circles. These queries can turn into fully fledged information-seeking expeditions. The burden of bureaucracy can be overwhelming, and we are no different to our non-disabled peers in that we have the same number of hours in the day. There are also issues in relation to physical access and the built environment specifically part M which my colleague James Cawley can address if Committee members wish to ask questions on this issue.

I have not had the privilege of always living with privacy, dignity, and discretion. Everything I turn my hand to, there are multiple government departments who need to be notified and several separate administrative offices. One of the most recent examples of this was my debacle with being offered a scholarship to study to a PhD level in early 2021. The modest stipend was a bone of contention regarding my disability allowance – I was going to lose everything. I instigated both a public and behind-the-scenes political communication campaign. While it is a rather long story of how Catherine's Law came to be, the crux of what I want to highlight today was the lengths I had to go to establish the lay of the land. When I received the first letter from the Department that I was to lose everything, I did not receive a reason why. I set about establishing the who, what, when, where, why and how of the matter. I received incorrect information on several occasions, including the leading statutory body that supports the provision of information.

I eventually managed to piece together a case and to be fair, when I presented it, I came across little resistance. There were organisations and politicians who may not have even been aware it was an issue. In the Dáil, it was described by one of the government party leaders as a 'mistake'. It certainly wasn't, but everyone got a fast education.

The physical toll that this pressure put on me – even before it went public – is indescribable. There was nothing private, nothing dignifying and nothing discrete about those couple of months.

When we think of coalition-building, we often think of it being external to us, or forming governments. Internal and cross coalition-building is just

as important in how we talk and work with each other. We need to acknowledge that there are departments and state bodies that would benefit from an overhaul in how they provide information to target groups, so that individuals can make informed decisions over their own lives. There are disabled people who have the expertise to aid with this. Consult with us – and better yet – hire us.

As it happens, I am in the middle of preparing an application regarding my research. I am asked to outline, in detail, how I will disseminate my knowledge, what impact it will have, who and where it will be useful for, and how it will add to the 'state of the art'. These are questions we also need to consider in light of accessible information and communication.