



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. According to the CSO there were a total of 643,131 people who stated they had a disability in April 2016, accounting for 13.5 per cent of the population. As one of the few Disabled Person’s Organisations (DPO), we are uniquely placed to make a submission on the “added costs” our members, disabled people incur while trying to live an independent life.

Independent Living is about having the freedom to have the same choices that everyone else has in housing, transportation, education and employment. It is about choosing what aspects of social, economic and political life people want to participate in, However due to barriers to accessing education and employment and with the added costs of disability, disabled people are one of the groups most at risk of deprivation and consistent poverty. Some Disabled people are less likely to achieve higher education or have a job but still face higher costs for many things including everyday items but even still disabled people who have went through education, secured a job etc. face economic inequalities from day to day. Inequalities that can be a barrier to citizenship and participation within the community and society. Disabled people nationally and internationally incur many extra living costs when living with a disability. These include additional heating, disability aids and equipment, drugs and other medical costs, costs in relation to personal care or assistance, transport costs. The impact of having to purchase additional equipment, special food / diets, increased electricity and water usage are so extreme, in many cases, that non-disabled people will never fully understand them. These increased costs mean that we as disabled people have significantly less disposable income or in some cases, due to lack of income, we may have to make difficult choices (such as choosing expensive medication over fuel costs, for example).

The cost of disability has been raised by the disability sector for over fifty years. The government should develop a cross-department measure to develop a minimum adequate income that is responsive to the extra costs associated with living with a disability, and ensure that we receive this income to support us, disabled people to live independently. Therefore the government must introduce a Cost of Disability payment and the government should equality-proof budgets and policies to eliminate discrimination and promote equality.

The cost of disability must be viewed in relation to the level of need and disability as every disability has a “cost” element. A person’s family should not be taken into consideration when accessing means.

- As acknowledged by the National Disability Inclusion Strategy disabled people are more likely to live alone and 42% live in a jobless household, putting them at high risk of poverty. Moreover, disabled people experience high levels of consistent poverty.
- The way out of poverty is imagined through “making work pay” for disabled people. However, lots of disabled people are still afraid to enter the workforce in fear of losing secondary supports and will not get certain adequate supports such as Personal Assistance Service to help them participate in employment. The Comprehensive Employment Strategy (CES) is a whole-of-government approach to increasing employment outcomes for disabled people and from December 2018 the disregard for Disabled People on Disability Allowance (DA) from €120 to €427 per week came in but there is still fear among the disabled community of loss of medical card, travel pass etc. which impact on the participation within the workforce. However the Public-sector duty sets to address many of the disabling aspects of our society, including government departments, local authorities, the HSE and others in taking steps to promote equality and human rights and remove discrimination. The UNCRPD requires States to ensure the right to work and other rights within the articles for example an adequate standard of living – however unemployment and sourcing adequate housing and poverty is an issue for disabled people and the UNCRPD recognises this.
- Direct payments initiative is a welcome start but it needs to be more nuanced in its approach to disability, allowing the person to use the payment for other crucial things including Personal Assistance Services rather than service providers and charities administering these services with high administration tiers and little actually trickles down to the disabled person themselves. We have a chance with the direct payments to bring about true equality. Similar to personal independent payment in the UK.
- The Mobility Allowance was a good scheme, and it worked. It became crucial to disabled people’s basic income. There needs to be a similar scheme but with more flexibility and choice for the person themselves.
- Transport for disabled people carries additional costs e.g. cost of someone to travel with you (if you don’t qualify for free travel card or companion pass). The cost of taxis to travel to meet accessible transport routes especially with the cuts to Mobility Allowance/Motorised Transport Grant. Supports to maintain your own transport E.g. tax and fuel relief and adapted learning vehicle and adaptations to vehicle need to stay in place otherwise we will incur extra cost on already large expense for disabled people to drive and maintain own transport.

- While increases in Disability allowance is always welcome, the government needs to invest in more accessible transport so that disabled people can travel for less or free without the barriers of booking systems or an environment that is not inclusive.
- Remove Taxation measures that penalise Disabled People. Specific products and supports that allow people to live independently and are such as wheelchairs, adaptive technologies, and adapted beds and so on should be exempt from VAT for disabled people. Mobility Aids and appliances should be VAT exempt without the need to use an Occupational Therapist (OT). There is a massive cost associated with mobility aids and a significant mark up by suppliers, our market could be opened up to EU sellers with lower costs and a reduced VAT rate. Domestic tools which are accessibility tools within the home are not always inclusive in tax exemptions i.e. Cordless hoovers for the blind. While some disabled people require additional heat in the home too.
- If working with a disability and over the income threshold you do not qualify for social housing or supports such as HAP. The private rented market is not equipped for disabled people often incurring larger rents. No tax exemption for disabled homeowners on property tax however there is exemptions for adaptations for physically disabled people.
- Sensory toys, aids and appliances for those with sensory processing disorders and everyday items such as eating aids and adapted utensils / wipes / gloves / tissues and drinking straws for those physically disabled are not covered under the medical card prove an additional cost to those who need them. Despite having a medical card individuals with secondary multiple health issues may incur an additional cost on repeat prescriptions. Other costs relate to: health and therapy services e.g. not enough adequate physical therapy so some pay private.
- Assistive technology – specially adapted computer technologies for independent living cost more while technology to aid those with sensory disabilities for example the blind is expensive and some grants are in place however most suited to most up to date mobile smart phones, however the person incurs the cost.
- Some guide dog owners on social welfare payments feel they have to fund their veterinary expenses and have their own pet insurance to pay.
- The Long Term Illness Scheme is unduly restrictive, some impairments for instance (congenital myasthenia gravis) is not listed even though all the prescribed drugs are listed for other conditions on the scheme. People with these impairments feel they have been forgotten by the state and there is an unequal burden regarding the lifesaving medicines that we must pay for if we do not have a medical card. Moreover, this is an example where there is little in the way of recourse or information about getting an impairment/disorder on the LTI scheme. Therefore one must either pay a significant cost per month or keep a low income job to meet the medical card criteria.

Further info and studies in relation to cost of disability:

The link below introduces the topic of [cost of disability](#) and refers to the 2004 study carried out by the NDA. The study was managed by Eithne Fitzgerald who has since retired from the NDA.

Center for Independent Living [Pre budget submission 2018](#)

[CIL Living Leader Forum Employment Report](#)

[CIL Living Leader Forum Transport Report](#)

[Public sector duty](#)

A specific study into higher costs arising from blindness and vision impairment was carried out by the Vincentians research unit for [NCBI](#) in 2017/18. The study is called Minimum Essential Standard of Living. The Vincentians carried out a similar study in the UK before their smaller Irish focused study.

[National Disability Inclusion Strategy](#)

[Comprehensive Employment Strategy](#)

[Make Work Pay](#)

[Poverty and Disability](#)

A number of reports and studies recommend a Cost of Disability payment, including the National Disability Authority's 2004 report 'Disability and the Cost of Living', the Commission on the Status of People with Disabilities and the National Economic and Social Forum.