



**CENTER FOR INDEPENDENT LIVING
CLG**

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**Center for Independent Living Pre-Budget Submission
June 2018**

1. Who is CIL?

The first Irish Center for Independent Living (CIL) was established in in 1992 by and for disabled people with the main aim of ensuring that disabled people achieved Independent Living, choice and control over our lives and full participation in society as equal citizens.

We have a campaigning and national representative role to promote the philosophy of independent living and to build an inclusive society. Central to the way we work is to ensure that the policy decisions, which impact on our lives, have to be directly influenced by those with a lived experience of disability.

Our philosophy can be summed up as: 'Nothing about us without us!' and 'Rights Not Charity'.

Our Vision

Our vision is an Ireland where disabled people have freedom, choice and control over all aspects of our lives and can fully participate in an inclusive society as equals

Mission

We are working collectively to create an independent living movement in Ireland led by disabled people, promoting a rights-based social model of disability, challenging

the 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.

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

Our Principles

- We will promote the active participation of leaders in all aspects of the work of CIL: locally, regionally, nationally and internationally
- We are a DPO (disabled persons organisation) formed to ensure 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, socioeconomic 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 medical / charity model of disability
- We are committed that CIL continue to develop new innovative models to achieve equality.

What is Independent Living?

Independent Living is the right of all persons regardless of age or impairment to live in the community; to have the same responsibilities and range of choices as everybody else in housing, transportation, education and employment; to participate in the social, economic and political life of their own communities; to have a family; to realise their own potential and have the freedom to live the lives they wish to in an inclusive society.

What is a Leader?

A Leader is a disabled person who employs directly or indirectly (through a service provider) Personal Assistants. A Leader takes full responsibility for the instructions given to the Personal Assistant, for training and the day-to-day management of the service. As a Leader I am in charge.

CIL's Proposals for Budget 2019 in order to promote equality and inclusion for disabled people in Ireland

1. Ensure commitment to equality and human rights budgeting in the Programme for a Partnership Government meets the needs of Disabled People

The Center for Independent Living welcomes commitments in the Programme for Government in relation to equality and human rights budgeting and the development by the Department of Public Expenditure of a new ex-post Social Impact Assessment (SIA) Framework to support a more comprehensive assessment of the impacts of budget measures on household outcomes. CIL stresses the need for disability and the costs of disability to be factored into any new SIA framework to measure the impact of budgetary measures on disabled people.

While these new developments offer a valuable potential to reinforce a coherent and effective approach to equality and human rights, most of the initiatives listed are limited to ex-post assessments. They do not go far enough to look beyond taxation and income to include targeted investment in infrastructure (housing, transport, education), to reduce inequality, or indeed equitable measures to increase the fiscal space to fund such measures to reduce the economic and social inequality experienced by disabled people.

Action: In order for Government Department's to meet legal requirements under the Public Sector Duty (see below), equality budgeting will need to be robustly applied to adequate and appropriate expenditure to meet our needs.

Equality Budgeting needs to recognise the specific infrastructural investment necessary to promote inclusion for disabled people with regard to the provision of accessible services in relation to transport, housing and employment.

Equality budgeting measures need to move beyond SIA Frameworks and include measures relating to investment in public services that can reduce inequality. They will also need to develop an accurate measure of the cost of disability.

2. Taxation and Investment

Budget 2019 must look to undo underinvestment in much needed infrastructure and supports for disabled people that have been removed over the course of austerity. In order to provide appropriate services and supports, we urge the Department of Finance to resist calls for reduction of taxation and to move beyond what is possible within the current fiscal space.

Equality and human rights proofing the budgetary process will require increased income to resource public services. Ireland continues to have one of the lowest tax takes as a proportion of GDP and not surprisingly, our public services remain under-resourced and undervalued. Equality budgeting should provide a basis for determining how progressive taxation measures, such as a wealth tax and inheritance taxes could provide the resources needed to promote equality and build a genuinely inclusive society.

Action: Building an inclusive society based on universal access and equality needs to be resourced through progressive taxation measures to invest in public infrastructure.

3. Ensure Budget 2019 meets standards set out in the Disability Act (2005) and the Irish Human Rights Equality Act 2014 Section 42 (The Public Sector Duty) and International Conventions and Covenants Relevant to Disability Rights

The Department of Public Expenditure and Reform needs to ensure that measures set out in Budget 2019 reinforce existing Statutory Commitments that Public

Investment should increase equality and inclusion for disabled people and that no use of exchequer funds should further marginalise or exclude us.

Specific reference needs to be made to the Disability Act 2005, namely Section 27 “Where a service is provided to a public body, the head of the body shall ensure that the service is accessible to persons with disabilities.”

The Department also needs to be compliant with legal obligations of the Department under Section 42 of the Irish Human Rights and Equality Commission Act (often referred to as the Public Sector Duty). Section 42 (1) states:

A public body shall, in the performance of its functions, have regard to the need to —

- a) eliminate discrimination,
- b) promote equality of opportunity and treatment of its staff and the persons to whom it provides services, and
- c) protect the human rights of its members, staff and the persons to whom it provides services.

Budget 2019 needs also to recognise International Covenants and Conventions that Ireland is a party to.

Ireland recently ratified the **UN Convention on the Rights of Persons with Disabilities** and a number of articles are relevant in developing Budget 2019, and in particular the need for investment in infrastructure and supports to enable us to live as equals in an inclusive Irish society:

Article 4 (General obligations) section 2 states that in relation to economic, social and cultural rights signatory states should undertake “measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law”

Article 19 (Living independently and being included in the community) is especially relevant given that it calls on States to “recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

The **UN International Covenant on Economic, Social and Cultural Rights** is specifically relevant to ensure that we have the freedom and choice to live our lives, and resources should be directed towards supporting this freedom, namely:

Article 1, Part 1: All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.

Article 2, Part 1: Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.

Action: In development of Budget 2018, CIL calls on the Department of Public Expenditure and Reform and the Department of Finance to work with all Government Departments to meet legal standards and international conventions to promote real inclusion of disabled people in Ireland.

4. Personal Assistance Service

The Personal Assistance Service (PAS) is a tool that allows disabled people to live independently. The PAS provides us with the freedom and flexibility needed to live our lives as we chose as it enables us to do all the tasks that we cannot do for ourselves.

It is important to note that the PAS is not a Care service. The tasks that disabled people require assistance with can range from personal care to domestic duties to assistance in carrying out paid employment or socialising

With a PAS a Personal Assistant (PA) is hired to assist with a range of day-to-day tasks that Leaders delegate to PAs and in doing so to take back control of our lives. A distinct benefit of PAS is that it reduces dependence on family and friends. The confidential relationship that develops between our PAs and Leaders enables us to maintain a private life and is based on respect and dignity. Essentially for many it is the difference between existing and living.

By leading and managing our own PAS' we remove ourselves from the traditional carer / patient relationship and are instead placed in control of our service. The PAS understands that there is no 'one size fits all' approach. With PAS, the Leader is the person who decides what supports are needed, and the Leader choses what support is needed to live our lives to our full potential.

The PAS is one of the four pillars of independent living along with housing, transport, employment and transport. However cutbacks in investment and diminution of the service has led to a service that cannot adequately meet our needs to live independently.

According to information submitted by the HSE to the Committee on Public Petitions, in 2017, 1.51 million service hours were delivered to 2,470 people. The allocation of hours of personal assistance were broken down as follows:

- Number of leaders in receipt of 1 - 5 hours per week: 1,097 (31.59% of total)
- Number of leaders in receipt of 6 - 10 hours per week 570 (23.07%)
- Number of leaders in receipt of 11 - 20 per week: 419 (16.96%)
- Number of leaders in receipt of 21 - 40 per week: 241 (9.75%)
- Number of leaders in receipt of 41 - 60 hours per week: 67 (2.71%)
- Number of leaders in receipt of 60 hours plus: 65 (2.63%)

71.62% of all Leaders in receipt of personal assistance service received less than three hours per day, with 31.59% of leaders in receipt of 42 minutes per day.

It is clear that anyone who receives an average of 42 minutes per day is not going to be able to live independently, access education or employment or become involved in meaningful social engagement. Disabled people with reduced services of this nature will become trapped in their own homes without the chance to interact and will be prone to isolation and depression.

Funding of €1.772 billion was allocated by the Health Service Executive (HSE) for disability services in the National Service Plan 2018. Of that, 89% of the budget was allocated to residential care and day services, with the remaining 11% allocated to respite care, personal assistance, home support services and community-based allied healthcare professional services.

It is clear from the above figures that hours for the PAS (which supports independent living) are being conflated with home care and home help services.

Action:

Leaders have noticed a trend whereby the PAS is moving away from its tradition to provide supports based on needs for disabled people to live real independent lives. This is borne out by the fact that HSE figures show that 71.62% of Leaders in receipt

of PAS in 2017 received less than three hours daily which is inadequate for us to live real independent lives.

We need clear legislative protection to protect a real Personal Assistant Service that supports independent living and a clearly ring-fenced annual budget solely for PAS, separated out from home care and home help supports.

5. Cost of Disability Allowance

Disabled people incur additional costs in our lives relating to our impairments, lack of appropriate local services and medical costs. The nature of the extra costs vary significantly across different impairments, with some of the main costs covering specialist equipment such as wheelchairs, alterations to the home, increased heating, electricity, and transport costs. These increased costs mean that we have significantly less disposable income, and coupled with significantly fewer disabled people in employment, leaves many of us at risk of poverty.

Action: The Department of Social Protection, in conjunction with the HSE and appropriate stakeholders, 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 to live independently.

6. Remove Taxation measures that penalise Disabled People

Specific products and supports that allow people to live independently and are such as wheelchairs, adaptive technologies, adapted beds and so on should be exempt from VAT for disabled people. Specific measures that are needed by disabled people are not luxuries and removing VAT this would ensure that vital supports are not adding to the cost of disability (see above).

Action: The Department of Social Protection, in conjunction with the HSE and the Department of Finance need to recognise that supports for disabled people are vital and not luxuries and be exempt in order that disabled people can access technology

and supports for them to live independently without incurring extra costs associated with VAT.

7. Housing and Disability

Having a home is crucial to living independently. The State's own commitment to supporting disabled people to live independently is outlined in the HSE's **Time to Move on from Congregated Settings: A Strategy for Community Inclusion** (2011) which "envisages that people living in congregated settings will move to dispersed forms of housing in ordinary communities, provided mainly by housing authorities".

Yet sadly, many of us are not aware of the possibilities of independent living. Many are still in residential settings. Younger disabled people are often the "hidden homeless" - they live in their parent's home, but do not have their own home or independence.

Research undertaken by the Irish Human Rights and Equality Commission (IHREC) and the Economic Social Research Institute (ESRI) in June 2018 showed that disabled people are "among the most disadvantaged groups. They experience high risks of discrimination and housing and environmental deprivation, and are particularly over-represented among the homeless population: more than one-in-four homeless people have a disability". The number of disabled people experiencing homelessness increased by 290, from 1,581 to 1,871, representing 13.6 % of the total homeless population.

The Report also noted that disabled people are 3.3 times more likely to report discrimination when looking for housing compared to those who are not disabled, specifically in the private rental market. The Summary of Social Housing Assessments (SSHA) for households with disabled people shows an increase from 3938 in 2013 to 5772 in 2017 which shows increased need for social housing to be built to ensure our housing needs will be met.

Action:

While the Rebuilding Ireland sets out a target of bringing 47,000 social housing units on stream by 2021, there are few specific targets relating to homes for disabled people. Investment in social housing needs to be ensure that social housing is designed and built in consultation with us and meets best international practice for universal design, to meet the current and future needs for access to social housing. Specific targets for housing for disabled people need to be based on analysis made by each local Housing and Disability Steering Groups with reviews annually, as per obligations under the Section 42 of the Irish Human Rights and Equality Commission Act 2014.

8. Employment

A report published by the ESRI last year found that disabled people in Ireland are four times less likely to be employed. The report found that, despite wanting to work, we are less likely to get a job. In 2017, 31 per cent of working-age people with a disability were at work compared to 71 per cent of those without a disability.

Action:

Budget 2019 needs to allocate resources in order to meet commitments to implement the Comprehensive Employment Strategy for Persons with Disabilities, and targets set in the National Disability Inclusion Strategy 2017 - 2021, including an increase of the public service employment target from 3% to 6%.

Budget 2019 needs to ensure that in resourcing Public Sector Recruitment in 2019 that stakeholders actively engage to develop special public service competitions and the opening up of alternative recruitment channels to target suitably qualified disabled people to take on roles within the Public Service, with supports provided as required.

9. Transport

Investment in a regular, accessible public transport service that links rural and urban areas is of vital importance to supporting us to live independently. Accessible public transport needs to be addressed as a priority in Budget 2019 to ensure that any investment in our public transport infrastructure further enhances inclusion rather than increasing marginalisation.

Under austerity budgets, transport supports for disabled people, such as the motorised grant scheme and mobility allowance, were discontinued. Budget 2019 needs to resource the impending Health (Transport) Bill to restore much needed supports for us to access transport and live independently.

Isolation is a reality for many of us. Research carried out by the National Disability Authority (NDA) in 2017 showed that disabled people were significantly less likely than those without a disability to have taken a holiday at home (36% versus 53%), gone on a day trip (55% versus 75%) or had a hobby (67% versus 82%).

Lack of transport continues to create a barrier to our participation as equals in Irish society. The NDA research also showed that we were significantly more likely to be at high risk of social isolation as measured on the Lubben Social Network Scale - 6. Thirty-two percent of disabled people are at risk of being socially isolated versus 22% of non-disabled people.

We also reported a significantly lower level of satisfaction with life (7.3 versus 8.0 out of 10) and were less happy (7.4 versus 8.2 out of 10) than the non-disabled people surveyed. A higher proportion of disabled people compared with non-disabled people felt tense (19% versus 4%), lonely (16% versus 4%), and downhearted and depressed (18% versus 4%). There was no variation in the levels of trust expressed between those with and without a disability. We also reported more social isolation (32% versus 22%) and less participation in social activities than non-disabled people.

The Health Research Board National Physical and Sensory Disability Database (NPSDD), collates information that outlines the specialised health services currently used or needed by people with physical / sensory disability. Since 2004, the NPSDD introduced the Measure of Activity and Participation (MAP) for self-reporting the barriers and challenges to participation, participation restriction and the WHO disability assessment.

The Annual Report of the National Physical and Sensory Disability Database Committee 2016 shows that the climate / weather (4,532, 56.0%) and the physical environment (4,452, 55.0%) were found to be the greatest barriers to participation, followed by income (3,436, 42.5%).

Socialising (4,680, 57.8%), shopping (4,522, 55.9%), and sports or physical recreation (4,241, 52.4%) were the areas where participation restriction was most likely to be experienced.

Being able to participate in activities such as socialising, shopping and sports in rural areas is often based on access to transport. The development of Budget 2019 needs to be aware of section 26 (1) of the Disability Act (2005), specifically section a (highlighted in bold):

- a) where practicable and appropriate, ensure that the provision of access to the service by persons with and persons without disabilities is integrated,**
- b) where practicable and appropriate, provide for assistance, if requested, to persons with disabilities in accessing the service if the head is satisfied that such provision is necessary in order to ensure compliance with paragraph (a), and
- c) where appropriate, ensure the availability of persons with appropriate expertise and skills to give advice to the body about the means of ensuring that the service provided by the body is accessible to persons with disabilities.

Action:

Investment in Rural and Urban bus and rail infrastructure must be based on international best practice stock to ensure universal access. The NTA needs to engage with DPOs, as per its legal commitments under the Irish Human Rights and Equality Commission Act (2014), to assess the human rights and equality issues in the development of public transport in Ireland and put appropriate time lined plans in place to address these issues.

The imminent Health (Transport Support) Bill which aims to update the long-defunct motorised transport grant for disabled people needs to be resourced to ensure we have access to appropriate supports to access transport.