



**CENTER FOR INDEPENDENT LIVING
CLG**

Carmichael House
North Brunswick Street
Dublin 7, Ireland
Tel. +353-1-8730 455 /8730 986
Fax +353-1-8730 998

<http://www.dublincil.org>

**Center for Independent Living Submission on the Personal Assistance Service
to the Joint Committee on Public Petitions
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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 their 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 policy decisions which impact on the lives of disabled people 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 peoples 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 led by disabled people, promoting a rights-based social model of disability, challenging a charity / medical view 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

Our Key Achievements

- CIL introduced the first personal assistance programme in Ireland thereby enabling people to take greater control of their lives. This has been the single most significant development for Independent Living in the history of the State.
- CILs is recognised internationally and have established invaluable links with key organisations and individuals across Europe and continue to actively seek transnational partnership opportunities.

- CIL Ireland is a founder and active member of the European Network on Independent Living (ENIL).
- As a Disabled Person's Organisation (DPO), it is led by disabled people and has always been based on lived experience
- CIL established the Certificate in Disability Studies in conjunction with NUI Maynooth
- CIL established Vantastic - an accessible transport system. Transport is a key disability issue and the introduction of Vantastic has offered many new opportunities to disabled people
- CIL has demonstrated that it can work effectively and in partnership with a wide range of voluntary and statutory agencies in order to bring about equality for disabled people

2. 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 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.

3. What is a Leader?

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 day-to-day management of the service. The Leader is in charge.

4. CIL's Expertise on the Personal Assistance Service

The Center for Independent Living introduced the first personal assistance programme in Ireland. It has supported disabled people who direct their personal assistance service ("Leaders") through training in the philosophy of independent living to ensure they are empowered to greater control of their lives. CIL supported the development and formation of other Centers for Independent across the country

which provide Leaders with personal assistants employed through HSE funding and Community Employment Schemes.

The Personal Assistance Services that are now available in Ireland came into existence in 1992 with a two-year pilot project that was initially run by CIL. It was recognised that in order to further the Independent Living Movement in Ireland, a consumer controlled Personal Assistance Service would be essential. The key idea was a service which would assist disabled people in all aspects of daily living, provide assistance rather than care and is directed and controlled by the service user.

The programme, funded under the European Union Horizon Community Initiative, started in December 1992. It involved 29 leaders and 45 personal assistants. The programme aimed, for the first time in Ireland, to develop a range of personal assistance services managed and controlled by disabled people . It also sought to ensure that personal assistants were themselves educated and trained in the skills, knowledge and attitudes required to provide a professional Personal Assistance service.

This CIL action research programme aimed to promote and develop the concept of independent living for people with significant physical impairments and, in particular, to research, design and implement programmes aimed at Providing a range of appropriate Personal Assistance services (PAS) and educating both Leaders (Participants with physical impairments) and Personal Assistants (PA) in the acquisition of positive attitudes and skills pertinent to the realisation of efficient services in this area.

The Final Evaluation conducted on this project in 1994 highlighted a number of benefits and results. These were:

- The positive effect on individuals being able, for the first time, to take control of their own lives and exercise choice
- Ending of dependence and ability to see independent living as right not a privilege.

- Enhanced social participation and involvement.
- Improvement in education (27.5% were able to use the PAS to attend college).
- Improvement in training options (18% were able to avail of further training).
- Improvement in employment access and conditions (50% noted enhanced employment options as a result of the project).
- Improved subjective sense of awareness and empowerment.
- Development of knowledge and skills.

There is no doubt that this project made an important impact in the quality of life for those disabled participants . It also provided training and employment opportunities for the Personal Assistants – as well as providing professional training and skills in this new field. At wider level the project indicated the potential for development and expansion of the concept and practice of independent living. The improvement in opportunity offered by this initiative would resonate in CIL and provided the foundation for much later progress.

After the success of the pilot project the administration of Personal Assistance was entrusted to Service Provision Agencies, such as the Irish Wheelchair Association, and Enable Ireland, although some regional CILs remained involved with Service Provision.

In the course of consulting our members for our new strategic plan (2018 - 2020), building awareness, support for and resourcing the personal assistance service was identified as a core strategic objective for CIL as a national representative organisation.

In order to develop a lobbying campaign based on lived experience of leaders nationally, CIL consulted with leaders on how we could develop a collective political campaign to ensure that the Personal Assistant Service fully supported Independent Living. Consultations took place in Donegal, Leitrim, Roscommon, Galway, Tullamore, Clare, Waterford and Cork with over 100 Leaders.

The following paragraphs represent the collective thoughts, experiences and aspirations of disabled people who currently are leading their Personal Assistant Service from across those eight regional consultations.

5. What Independent Living Means to Leaders:

Independent Living is about equal rights and opportunities; it is about my freedom to choose and my right to make decisions about everything that affects my life.

Independent Living is a way of looking at disability and society. Am I disabled because of my impairment or am I disabled by the lack of accessibility within the community I live in? If the health, employment, education and other services that I need to access, on a daily basis, were fully accessible and inclusive would I still experience the same barriers? Independent Living looks at society and sees me as a key part of it. To participate I need to have access to the range of supports and services that I need to live the independent life that I chose.

Independent Living is for all of us, regardless of our level of impairment or needs. It is unique in that my life will differ from yours and therefore the supports I need to live will also differ. However, our ultimate goal will remain the same – to live in a society that is fully inclusive with all the rights that this entails. Therefore Independent Living will have common values for each of us including:

- Giving me the freedom to make my own decisions but also my own mistakes.
- Offering me choices and the ability to live my own life without feeling I need to always rely on my family or friends.
- Enabling me to live a full life both inside and outside of my home.
- Empowering me to use my voice both to speak and be heard.
- Recognising that I can contribute to society at many different levels.
- Giving me the privacy to live my life as I chose.

6. What does the Personal Assistance Service mean to Leaders?

The Personal Assistance Service (PAS) is a tool that allows us to live independently. PAS enables us to do all the tasks that we cannot do for ourselves. It provides us with the freedom and flexibility we need to live our lives as we chose. With a PAS a Personal Assistant (PA) is hired to assist us with a range of day-to-day tasks that we cannot physically do for ourselves. We delegate these tasks to our PAs and in doing

so take back control of our lives. It is important to note that a PA is not a Carer. The tasks that we require assistance with can range from personal care to domestic duties to assistance in carrying out paid employment or socialising.

A distinct benefit of PAS is that it reduces our dependence on our family and friends. The confidential relationship that develops between our PAs and us allows us to maintain a private life and our dignity. Essentially for many it is the difference between existing and living.

7. Why Leaders feel the Personal Assistance Service Differs from other supports like home help

Personal Assistance Services are a unique two-way relationship. With other care models the person is removed from the relationship and the focus is placed upon the task that needs to be completed. There can be a lack of flexibility and I may feel frustrated due to the limitations placed upon me. This places restrictions upon my life and doesn't recognize my ability to live a productive life outside of my home.

By leading and managing my own PAS, I am removing myself from the traditional carer/patient relationship and instead placing myself in control of my service. I respect my PA but understand that I have the ability to direct and control my own life. The PAS understands that there is no 'one size fits all' approach. With PAS I am the person who decides what support I need. I have a right to have a choice. My service provider should then provide the support I need to enable me to live my life to my full potential.

8. How the Personal Assistant Service needs to be protected and Strengthened

As Leaders we 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. Restrictions on lack of hours and limitations on how we can use our hours, such as the ability to use our PA hours to allow us to socialise, are increasing levels of isolation and pushing us back toward a medical approach to disability. As we look toward rebuilding our solidarity movement we will focus on the following key areas.

Policy and Research:

- a) **Protect our PAS:** Ireland has stepped toward a commitment to Independent Living through ratification of the UNCRPD however the very tool upon which it is based is still not legislated for. The Personal Assistance Service remains a pilot project that is dependent upon funding. We need clear legislative protection to protect our most basic of human rights and a clear ring-fenced annual budget solely for the PAS.
- b) **Demonstrate the Cost Effectiveness of the PAS:** Although the economic benefits should not be the only justification for investing in Independent Living they are an important consideration. There is a considerable lack of data on the real economic benefits of Independent Living as opposed to residential care. This is particularly important given the number of disabled people currently living in inappropriate settings.
- c) **Cost Benefit Analysis of the Social Value of PAS:** Investing in Independent Living has a number of social and economic benefits that go beyond the actual cost to the taxpayer. As disabled people who are supported to live independently our traditional dependence on charity models is reduced. We have the potential to contribute to society through paid employment, as consumers and taxpayers. We also have the additional benefit of freeing family members to return to positions of paid employment.
- d) **Clearly Define the Number of People in Receipt of PAS:** As Leaders we recognise that there is a clear distinction between PAS and Home Help / Home Care services. Clarity needs to be provided on the number of disabled people who are currently in receipt of PAS in each Community Healthcare Organisation (CHO) area.
- e) **Protect our Personal Assistants:** Lack of job security and minimum wages have made it difficult to attract and retain quality PAs. PAS need to be supported in terms of career progression to protect the quality of service we require.

Education and Training:

- f) **Independent Living Awareness:** Each of us has the right to understand our entitlement to the services that we need to live independently. Additionally

education needs to be provided on the benefits of Independent Living for our families and for the public as the taxpayers who fund our services.

Leader Training: The journey into Independent Living can be daunting. There is a lack of understanding about what we should expect from our PAS and service provider. Leader training, which is delivered by a person with the lived experience, should be available as standard to all new entrants to PAS and for any Leader requiring additional support.