

The Joint Committee on Disability Matters ‘Resourcing Personal Assistance Services’. Thursday 8th July 2021. James Cawley, Policy Officer, Independent Living Movement Ireland, opening statement.

Cathaoirleach and members of the Committee thank you for the invitation to contribute today. Can I just start by thanking the committee on the series of inputs that were dedicated to article 19, I want to commend the deputies and senators who have engaged to date on these matters.

A little about myself. I’m a Son, Brother, Husband, Friend, Co – worker and a very proud disabled person who uses a Personal Assistance Service to live a life of my choosing. Growing up in rural Ireland and being the youngest of 9 siblings my independence and activism skills were fostered from a very young age. I went through education and progressed to University and now work in fulltime employment and live with my wife Ally. I received appropriate supports to live and experience life the same as my non-disabled peers. These included assistive technology, a powered wheelchair, peer support, an SNA, exam accommodations, accessible transport, accessible accommodation and Personal Assistance. These supports allowed me to make fundamental decisions and choices throughout my life. With that said I am very proud to be here this morning representing a movement of disabled people across Ireland in my role as Policy Officer with Independent Living Movement Ireland. I am going to talk about the following:

- Introduction to Independent Living Movement Ireland (ILMI) and the philosophy of Independent Living.
- What a Personal Assistance Service (PAS) is.
- ILMI PASNOW campaign.

Introduction to ILMI

Independent Living Movement Ireland (ILMI) is a campaigning, national representative cross-impairment Disabled Persons Organisation (DPO). We promote the philosophy of independent living and seek 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 must be informed by disabled people through our representative DPOs.

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.

ILMI was established as the first Irish Center for Independent Living in 1992 by and for disabled people in order that we have choice and control over our lives and participate fully in society as equal citizens.

The Personal Assistance Services – or PAS- that are now available in Ireland came into existence in 1992 initially as a CIL pilot project. It was started by disabled people who designed a system where they were in control of the direction, operation and management of their PAS.

However, 30 years on the PAS is still a pilot project with no legal right to a PAS in Ireland for disabled people despite having national policies that support de - institutionalisation of disabled people. In addition Ireland signed and ratified the UNCRPD of which article 19 states that disabled people have the right to choose where and with who they live and have the right to be included in the community. Ireland is rich in policy development however we need to work together to implement our policies to ensure our rights as disabled people are upheld.

I am now going to talk about the philosophy of independent living and what a Personal assistance service is.

Independent Living is about having the freedom to have the same choices that everyone else has in housing, transportation, education and employment. Independent living is also about choosing what aspects of social, economic and political life people want to participate in.

Independent living is about having control over your life, to have a family, to get a job, to participate socially and to realise your goals and dreams. When my Independent Living supports are in place such as my Personal Assistance Service - I can be that Son, Brother, Husband, Friend, Co – worker.

For many disabled people, Independent Living can best be achieved by the employment of Personal Assistants to provide supports where needed. The Personal Assistance Service (PAS) is a tool that allows us to live independently. The 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 choose. A Personal Assistant (PA) is hired to assist us with a range of day-to-day tasks that we cannot physically do for ourselves. Many of us say PA's are the "extension of our limbs" they are "our eyes" and "our ears".

With PAS we are in control and direct the PA to carry out tasks both inside and outside of the home, including personal care, domestic duties, assisting in day-to-day tasks such as shopping, support in the workplace or socialising. A PA does not "look after" or "care for" us. We delegate these tasks to our PAs and in doing so take back control of our lives.

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. The PAS is often the difference between “existing” and “living” for many of us.

To put this into context I will share this example with you all today:

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. However, these figures show that over 84 % of us who received a PAS received less than three hours per day on average, with over 44% of us in receipt of an average 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 are unable to live the lives of their choosing. They are often trapped in their own homes without the chance to interact and do the things they want to do in life. They are prone to isolation, exclusion, and institutionalisation in the home where they simply “exist” and not live!

I know there has been sessions dedicated to de – institutionalisation however, I want to make reference to wasted lives: Too many disabled people under the age of 65 are inappropriately placed in nursing homes or do not have the adequate and appropriate supports to live a life of their choosing. Can you imagine all your choices being taken away? Being told when to eat, drink, go to the bathroom, and go to bed? All your decision making taken away?

We as a National DPO support the philosophy of independent living. Independent Living is not just about living in a house it is about all the pieces of the Independent Living jigsaw fitting together. It is our choices, our control, our dignity, having appropriate and adequate supports to have that choice, that dignity and that respect to live a life of our choosing.

So, having told you about the philosophy of independent living and how the PAS is central to giving us control in our lives, I now want to outline what we as a DPO are calling for in developing a national system that meets the needs of disabled people.

What we in the Independent Living Movement Ireland (ILMI) have developed is a national campaign called PASNOW. It is based on discussions with disabled people all over the country who identified our 5 asks. To: Define, legislate, invest, standardise and promote the PAS.

Define: A universal accepted definition of the Personal Assistance Service, which places us at the centre of any service provided and is directed by us to meet our needs to live independent lives. The PAS is about providing us with the necessary supports, both inside and outside of our homes to enable us to live a life of choice, dignity and respect. The Personal Assistance Service needs to be separated from Home Help and Home Care with its own ring-fenced budget.

Legislate: Introduce legislation to guarantee us the right to a Personal Assistance Service as per Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

Invest: Increase the budget for Personal Assistance Services by €12.5 million annually to provide an additional 500,000 hours each year to enable us to lead real independent lives.

Standardise: Introduce a single standard assessment of need across all HSE CHO areas. This must include the provision and support for independent assessment of need as per the Disability Act 2005 and the creation of a national standardised system that will allow for portability of services across CHO areas, meeting our social, personal and employment needs with no bureaucratic barriers.

Promote: Ensure that we are all made aware of the availability of the Personal Assistance Service in order that those who wish to lead their lives independently can access the necessary supports to do so.

In summary, Independent Living is about choice and control, the PAS is about giving disabled people that control. We did ratify the UNCRPD in 2018 and what we as a DPO want is a system that meets the needs of disabled people including investment, standardisation and legislation to protect this right. We believe this would be a way to realise and implement article 19 of the UNCRPD.

I would like to take this opportunity to thank all members of the disability matters committee here this morning for listening and I look forward to your questions or comments.

References:

ILMI Observations State Report: April 2021 - see website.

ILMI PASNOW Campaign – see website.

ILMI website: www.ilmi.ie