

Submission to the Committee on Disability Matters

23rd March 2023

Opening Statement

Independent Living Movement Ireland

Irish disabled people were one of the first users of a Personal Assistance Service (PAS) in Europe, yet, over thirty years later, we are one of the few EU countries where disabled people do not have a right to this service.

Independent Living Movement Ireland's vision as a cross impairment Disabled Person's Organisation is an Ireland where disabled persons have freedom and self-determination over all aspects of their lives to fully participate in an inclusive society. We believe that a right to a PAS for disabled people is fundamental to achieving that vision. A right to a PAS, amongst other issues such as true representation, inclusive participation and real accessibility are fundamental for disability equality to be achieved in the state.

Firstly, I will define what a PAS is. 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 PAs 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 Personal Assistance Service is a central component of independent living. Disabled activists in Ireland were one of the first group of disabled people to successfully push and fight for a PAS and many hundreds of disabled people have led real and productive lives by utilising this basic tenet of modern social democracy. It has proven cost effective, liberating and a real marker of social justice for disabled people who need the service.

However, disconcertingly, Ireland does not give disabled people the subjective right to a PAS if they require one. The PAS budget is still combined with the overall homecare budget, and there is no definition of what a PA is across the CHOs and no standard assessment of need. As we witnessed in 2012, there is no commitment to giving us a right to this service and it can be taken away immediately. When we consider the massive social and economically positive outcomes of having a PAS (as the ERSI study has mentioned) then it begs the question why these issues have not been resolved.

For over 30 years, there has been campaigning, struggles and challenges to the PAS, all the time these predicaments met with resistance and tenacity from disabled activists, yet still the sword of Damocles perpetually hangs over us.

Despite ILMI and our allies' continual push for legislation, regulation and definition, successive governments have not meaningfully engaged with the issues. We welcome the research conducted by the ERSI which aligns with our own research and policies that are informed and led by the wider disability collective.

Through a nationwide consultation with our members, it is clear that some service providers are moving away from the original ideal started by disabled activists in 1992. This successful model was based on disabled people directing our PAS to enable us to live full lives of self-determination. Many feel the PAS is moving towards a system focused on compliance, regulation and bureaucracy.

ILMI has been running a campaign for investing and creating a system of Personal Assistance that meets the needs of disabled people called PAS NOW. Our campaign has been about five actions that are required to address the deficiencies that has been slowly, but persistently, occurring within the PAS. To do this, we need to have an agreed definition of the PAS, which places us at the centre of any service provided and is directed by us to meet our needs to live independent lives, separated from Home Help and Home Care with its own ring-fenced budget.

We need to standardise how need for PAS is assessed and ensure that there are no barriers to disabled people moving from one area to another for work, education or social reasons.

We need to see year on year budgetary increase in the budget for PAS, which can be achieved from redirecting funds from services that do not support the inclusion of disabled people in society.

We need PAS to be promoted so that disabled people who could benefit from support are aware that it is available.

And we need to 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).

The PAS is a tiny fraction of the overall HSE budget and a minuscule amount of the billions spent on disability services, but the effects it has is, in most cases, is life changing. Ireland is not living up to its ideals of a modern social democracy – it is not treating all its citizens equally, and it is not upholding the fundamental ideals of the UNCRPD which it has signed. Every local authority in the state has supported our call for a right to a PAS - that is democracy.

Because of the lack of clarity in relation to the PAS we are now seeing several issues. Service providers have moved away from the initial ethos of the service and it is being more and more aligned to a care role; with disabled people being less involved in the selection, rota or management of their service. Similarly, there is a challenge about PA recruitment and retention – these issues are rooted in the lack of a legal right to a PAS – in this vacuum there is no standard training programme for PAS nor is there any regular assessment of the services.

One example is the lack of continuity for young disabled people that may have a PAS in third level, but once they leave education they are either told to reapply or that there are no PA hours available. It seems that we are often giving young disabled people a taste of independence and then removing it from them.

For clarity - there are currently just over two thousand users of PAS in Ireland, not hundreds of thousands of disabled people, and many do not receive the hours they need to live the lives of their choosing. Many more disabled people, regardless of impairment, could benefit from some support both inside and outside their homes to live the lives of their choosing.

This is not a significant strain on the exchequer or society. Indeed it is the opposite, it is central to enabling many disabled people live, not just

survive. Ireland wants to be a paragon of modern social equality, forward thinking and open. Then let's start here. We hear at a Statutory level of a commitment to a rights-based, social model approach to disability, of moving away from a charity and medical model. Investing, standardising and legislation for PAS is fundamental to that approach. We do not need to reinvent the wheel; we can see how other EU countries of a similar size and social values do it properly. This is not a new issue, it is three decades in the making, and if this government (or the next) wants to be genuinely committed to equality, than this needs to be addressed as a priority to realise disabled people's rights under our commitments in the UNCRPD.

Thank you for listening and we look forward to answering any questions.