

Achieving a right to personal assistance in Ireland Summary Document

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 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. For many disabled people, Independent Living can best be achieved by the employment of Personal Assistants to provide supports where needed.

ILMI's 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. We believe that a right to a personal assistance service for disabled people is fundamental to achieving that vision.

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 chose. A Personal Assistant (PA) is hired to assist us with a range of day-to-day tasks that we cannot physically do for ourselves.

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.

In March 2018 Ireland formally ratified the UN Convention on the Rights of Persons with Disabilities (CRPD). Under Article 19 of the CRPD disabled people have the right to live in the community and have access to a range of in-home and other supports, including personal assistance, to support this.

Currently there is no legal right to personal assistance in Ireland. Those in need of this support often find the application process problematic, as there is no standardised procedure and those in receipt of this support do not have any security regarding the continuation or extent of their service due to lack of legislative protection.

In 2017, 84 percent of those in receipt of a PA service received less than three hours a day and 42 percent of these people were in receipt of between one and five hours a week. This is only an average of 42 minutes a day, despite there being 1,440 minutes in a day and disability being a 24-hour affair.

As far back as 1996, it was identified that an average need for 10 hours of PA service per person per week could only respond to essential personal care needs, not quality of life requirements and it would certainly not enable full active participation in the community.

Sweden has long been regarded as the ground-breaking country and 'gold standard' for personal assistance. It remains the only European country which legally confers a right to personal assistance, although there is some legislation in this area in many countries, such as Denmark, France, Germany, Latvia, Norway, Serbia, Slovakia, Spain and the UK.

Achieving a Right to Personal Assistance in Ireland shows that introducing stand-alone legislation is the most straight-forward way to recognise the right to personal assistance for disabled people. The comparative research conducted for this report shows that legislation will need to focus on the full, active participation of disabled people in society, including in education and employment.

This must be based on a comprehensive assessment of the individual's needs to determine the amount of personal assistance an individual will receive in order that they have choice, control and freedom to participate in society as equals.

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