

## Submission to the Joint Committee on Disability Matters

My name is Damien O'Reilly. I live in a rural area in County Cavan. I have a physical disability (Cerebral Palsy and impaired speech) due to lack of oxygen at my birth.

I attended both primary and secondary mainstream school. This was only possible due to my Mam's persistent fight for equality back in the early 80's, long before The Education Acts. During my primary education I relied on the goodwill of my friends and teachers for support during school hours and my Mam aided me in doing my homework.

It wasn't until half way through my third year in secondary school that I was granted a classroom assistant who acted as both scribe and interpreter. I completed my Leaving Certificate in 1999 and got accepted into DCU but due to lack of support i.e. the need of a Personal Assistant, I wasn't in a position to enrol in the course.

It was this lack of independence that motivated me to find out information about how I could obtain a PA service.

Over the next number of years, I became involved in many disability organisations and was a representative for Disability Federation of Ireland on the Health Service Executive's (HSE) North East Coordinating Committee for Physical and Sensory Disability for over five years.

I completed a self assessment and a brief outline of my daily routine and submitted it to my area manager in the HSE. Throughout this time, I was constantly discussing my situation with my peers such as the late Martin Naughton, who were involved in Independent Living. They had been managing their own Personal Assistance Service via a service provider for at least 15 years and informed me that securing a Direct Payment and employing a Personal Assistant (PA) was the only way I would achieve independence in my life.

Eventually after a long negotiation period the HSE responded positively and I was offered 40 hours per week which was less than half of what I needed to achieve total independence. I was given the choice of negotiating with service providers, including the HSE, to get best value for funding and to find a service that met my needs. As there was no service provider within the county providing a PA service, I contacted two well-known Not-For-Profit organisations to see if they were in a position to administer my hours which were allocated by the HSE. However, through discussions with both organisations it became obvious that it was not going to be economically viable for either organisation to administer my service. This is due to the fact that when the admin costs were taken from my budget, the remaining hours were insufficient for my needs.

I then undertook a Certificate in Training with the National University of Ireland, Maynooth, a business course with Cavan Partnership, and began drafting a work safety statement and researching sole trader and limited companies.

In 2008, I registered as a sole trader with the Central Registration Office (CRO) and set up a separate bank account for the business 'Independent Living Options' (ILO) and acquired a payroll service. The company also employs an accountant to audit the accounts every year. In order to comply with regulations from the HSE then had to create ILO invoices, time sheets,

medical clearance forms and safety statements and subsequently in 2014, I had to enter a Service Level Agreement with the HSE for governance purposes of my Direct Payment. This entailed compiling numerous new documents such as risk assessments, complaints procedures, health and safety policies, to mention a few. All of this was necessary to ensure correct management of my Direct Payment and ensure continuation of my service.

Upon completion of the establishment of the business and the necessary company documents, I sourced a local agency to provide support as an interim measure for the first few months.

I soon learned how restrictive this service was due to the agency working specifically under the medical model of disability i.e. the lady couldn't accompany me outside the house, couldn't do certain tasks in the house or couldn't give medication to me. Subsequently in March 2009, I employed my PAs directly through the company.

The defining difference between a PA and a carer is that the PA works completely under the direction of the person with the disability (Leader). They assist the Leader with everyday tasks such as personal care, social and domestic tasks that the Leader needs completed but they do not "care for" the Leader. Unlike a homecare service, there is no Careplan. They work under the social model of disability. A PA is often described as an extension of the limbs of the Leader.

I then trained my PA's myself under the social model of disability and being mindful of the philosophy of Independent Living. During the training, my mother interprets my speech at the start and assists with the Health and Safety aspects. My first priority when training a PA is to get them to a point where they understand my speech. This takes approximately three weeks. My PA's role as an interrupter to me is vital to my independence and my participation and interaction with other people who may not be familiar with my speech.

When the induction training is completed, the PA works solely under my direction at all times. This allows me to have control over my own life, make my own day to day decisions, as well as attend meetings, social functions, complete daily living tasks and achieve independence in my life.

On a number of occasions over the past 13 years, I have used Homecare agencies as a stop-gap measure in-between recruiting new PA's. I found that the service they provide, in comparison to a self-directed Personal Assistance Service, is totally inadequate. In addition to this, the associated costs of obtaining these agencies, results in less than half the amount of hours as you would if you were employing your own PA directly.

In my opinion, there is absolutely no accountability for these care providing agencies unlike a Personal Assistance Service where strict governance guidelines can be upheld by the person with the disability. This is due to the person with the disability being in control of their own decision making, their own service and their own autonomy.

This social model of disability underpins the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Article 19 of the UNCRPD states:

*“ Parties to the present Convention 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.”*

Providing people with disabilities with the opportunity to avail of a Personal Assistance Service, not only gives control back to the individual but it also fulfils Ireland’s commitment to Article 19 of the UNCRPD.

As there is no legal right to a Personal Assistance Service in Ireland, people currently negotiate on a piecemeal basis directly with the HSE. The lack of legislation and clarity around Personal Assistance Services, diminishes the rights of people with disabilities. The challenges I faced with obtaining a Personal Assistance Service are not unique to me, this is an obstacle my people with disabilities face throughout Ireland.

In 2019, as part of a national campaign, I lobbied my local County Council with a motion for the Right to a Personal Assistance Service which was passed unanimously at local level. Hopefully this is one small step to enshrining the legal right to a Personal Assistance Service for people with disabilities in Ireland.

In closing, I think it is important to create legislation underpinning the Right to a Personal Assistance Service and to promote Independent Living in Ireland subsequently upholding the principals of the UNCRPD.