



Statement to the Oireachtas Joint Committee on Disability Matters, on 'Inadequate personal assistance supports', 23rd March, 2023

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Thank you for inviting us to present evidence on personal assistance or PA supports in Ireland. We will be drawing on a large-scale, multi-phase study on personal assistance supports in Ireland we carried out in 2020 and 2021, with the findings published in two articles [[available here](#)¹]. The research was conducted as part of an ESRI-National Disability Authority research programme to explore important issues facing disabled people in Ireland today.

Our research reflects on the current personal assistance structures in place and on the experiences of disabled people as they negotiate and engage with personal assistance services that are intended to support their independent living. It draws on a two-stage mixed-method study with both institutional stakeholders involved in service provision and disabled people using PA services. As the research developed, it increasingly drew on a capability approach, focusing on the voices, preferences and experiences of PA service users and their reflections on the role of PA supports in supporting the functionings they want to achieve.

In line with Irish policy, we understand a personal assistant to be someone “employed by the person with a disability to enable them to live an independent life. The personal assistant provides assistance, at the discretion and direction of the person with the disability, thus promoting choice and control for the person with the disability to live independently”. However, most personal assistants are employed by service provider organisations on behalf of service users, using the funding allocated to that service user. Personal assistance has long been a key support for Irish people with physical and sensory disabilities, but prior research shows that Ireland lacks national standards for allocation, provision and data collection for evaluation of the service.

The first phase of our research considered aspects of PA provision from the perspective of insiders, gathering the views and experiences of service providers and state-based institutional stakeholders regarding the PA system and its challenges. Drawing on a series of qualitative interviews and a survey of HSE disability managers, the findings highlighted critical issues relating to underfunding, inadequate administrative data records and variation in allocation and provision across the country. This variation stretches across funding arrangements, needs assessment procedures, principles of provision, accountability requirements and the working conditions of the assistants. The findings gave us an understanding of likely issues facing service users in accessing adequate PA and directing their PA, with particular issues around the evaluation of needs and how this informs allocation.

The first phase provides a valuable backdrop to the second phase, where we address a particular gap in understanding the experiences of disabled people, completing a large-scale mixed-method study with PA service users. Overall, the evidence shows satisfaction among many service users, but suggests that systemic shortfalls have a clearly detrimental effect on the functioning and capabilities valued by the participants in relation to their ability to participate in everyday social and economic activities. The findings of this study provide valuable insights into what good personal assistance means for disabled people's everyday lives and what Irish PA service users want to see change in the system.

The evidence shows the impact of inadequate support on people's day-to-day lives. Most of those surveyed wanted a broader range of supports, with some effectively confined to their homes due to their lack of PA hours. Others were reliant on unpaid support from family and friends. As well as dissatisfaction over the number of hours, there were calls for greater control over when and for what their HSE-funded hours could be used.

More positively, there was a high level of satisfaction with the quality of existing PA, and especially with respondents' current service provider and/or personal assistants. Overall, the survey points to a significant appetite for change among PA service users and makes clear the impact of inadequate support across their lives.

As supports like PA are reformed and improved, it is vital that disabled people are meaningfully included in the design and evaluation of services they rely on. The research sought to model this approach by involving disabled people in the design of the study through an advisory group. The research highlights aspects of PA, existing or potential, particularly valued by service users:

Having a PA was felt by many to be necessary to enter and succeed in employment and education (ESRI research shows one of the lowest levels of employment among people with a disability across the EU). Currently, however, PA hours are not widely used for either. This was partly a result of explicit direction from some service providers, and from the HSE in some areas, that PA hours could not be used for employment, partly due to an overall shortage of hours and partly to do with issues finding PAs with the skills needed in the workplace or learning environment.

Insufficient hours were a huge barrier to social engagement, leaving many respondents isolated. When asked about what else they would like supports for, respondents mentioned things most people take for granted like trips to the cinema, shops or a café. In particular, leaving the house for events during the evening or at weekends was not possible for many.

The relationship with the personal assistant was central to respondents' perceptions of PA. Managing the personal and professional relationship was challenging, but when it worked it was immensely rewarding. Personal assistants' working conditions, especially their pay, hours and lack of progression opportunities, indirectly impacted service users as they made it difficult to hire and retain suitable people.

This research shows the importance of adequate and effective personal assistance for disabled people's quality of life. Disabled people face much worse outcomes than non-disabled people across the areas of employment, education and social engagement, and supports like personal assistance can help tackle that gap. At the moment, though, the supports do not go far enough to allow most service users to live a full and independent life.

¹ Carroll, E., C. Mac Domhnaill and S. McCoy (2023). Personal assistance services for disabled people in Ireland: "they meet the criteria for supports but we don't have the resources to provide the services", ESRI Working Paper 747, Dublin: ESRI, <https://www.esri.ie/publications/personal-assistance-services-for-disabled-people-in-ireland-they-meet-the-criteria-for>

Carroll, E. and S. McCoy (2022). Personal Assistance Services in Ireland: A Capability Approach to Understanding the Lived Experience of Disabled People, *Disabilities*, 2022, 2(4), 694-714, <https://doi.org/10.3390/disabilities2040049>