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PERSONAL ASSISTANCE SERVICES IN IRELAND: A CAPABILITY APPROACH TO UNDERSTANDING THE LIVED EXPERIENCE OF DISABLED PEOPLE

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Personal Assistance Services in Ireland: A Capability Approach to Understanding the Lived Experience of Disabled People[1]

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INTRODUCTION

A personal assistant is defined as 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". Personal assistance services are provided primarily to persons aged 18-65 with physical and sensory disabilities; persons with disabilities over the age of 65 are not eligible. Personal assistance (PA) has been a key support for disabled Irish people for many decades, but evidence shows that there is a lack of national standards for allocation, provision and data collection.

Our research examines whether PA users are satisfied with the PA service and whether satisfaction levels vary with their location, the level of support they receive, the length of time they have been availing of PA or other factors. We also examine challenges that PA service users encounter in using and benefitting from PA services and recommendations they have for changes and improvements to the PA system.

DATA AND METHODS

We conducted a large-scale mixed-method study with PA service users in summer 2021. We carried out a survey with 326 PA service users and follow-up in-depth interviews with 8 survey respondents with differing characteristics and experiences. We adopted a multimode survey approach—with options to complete the survey online, by post or telephone—as well as providing different options including plain English and easy to read versions. Our study was

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[1] This Bulletin summarises the findings from the following paper:

- Carroll, E., McCoy, S., 2022. Personal Assistance Services in Ireland: A Capability Approach to Understanding the Lived Experience of Disabled People, Disabilities, online 9 November 2022. https://www.mdpi.com/2673-7272/2/4/49

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[2] This research was funded by the National Disability Authority (NDA) as part of the Joint Research Programme, which focuses on the experiences of disabled people across key policy areas.

undertaken in collaboration with disability advocates and disabled persons organisations, with particular engagement on the study design and survey.

RESULTS

Overall, the median number of PA hours received is 10, with higher allocations among those with higher levels of education, those living in urban city areas and those with lower levels of “natural supports” (unpaid assistance from family or friends). There was significant dissatisfaction with the number of hours currently allocated, as well as with the constraints on when those hours could be used and what they could be used for. Overall, 38 percent of respondents said that PA assistance was meeting their needs compared to 40 percent who disagreed, and calls for more hours were by far the most widespread feature of the qualitative material.

In terms of the nature of the supports received, and how disabled people use their PA services, support for personal care and activities of daily living are prominent, indicated by 71 and 79 percent of respondents respectively. Assistance with social activities is indicated by just over half of respondents. Assistance in the workplace and assistance in education or training are less prevalent—with just 19 and 16 percent respectively currently in receipt of these supports. Interviewees highlighted that they were unable to get any workplace support hours and that this was a significant factor preventing them from working.

Many respondents were satisfied with the quality of their current supports, and especially with their specific service provider and/or personal assistants. At the same time, a significant majority wanted a broader range of supports to be available. Support for social activities was the most common specific support respondents would like to have access to. Unsurprisingly, the desire for extra support for the workplace or education was raised by many respondents. Transport was also an area of concern for many respondents, with difficulty in accessing medical appointments, attending suitable exercise classes, going shopping and getting out of the house reported, as well as travel more broadly to events like concerts and on holidays. Calls for greater breadth and depth of supports were common—for more hours, more types of support and greater funding in general as well as for better links to non-PA supports. There were also calls to make PA easier to access in the first place, both through making more information about it available for people who might be eligible and through improving the assessment and allocation process.

The relationship between PA service users and their personal assistants was central to respondents’ day-to-day experiences of PA. Challenges tended to reflect the lack of choice in selecting their personal assistant and challenges facing personal assistants in terms of low pay, poor conditions and lack of progression opportunities.

POLICY IMPLICATIONS

This study identifies areas where the PA system can be improved and indicates potential steps that could be taken to achieve this. While the increased hours called for by participants in this research would require a substantial increase in funding, the current level of expenditure on PA is a small fraction of the state’s spending on disability services. There is space for other potential reforms such as standardising how PA is allocated across the country and drawing up best practice guidelines for putting service users in charge of their own PA. This study also suggests that a necessary step towards improving the PA system is improving the conditions for PAs. Significant developments in Irish PA are planned over the next few years to meet growing demand, improve quality assurance and place PA supports on a statutory footing. This research provides policymakers with useful evidence on service user need and experience that can inform these changes, as well as highlighting the benefits of engagement with service users and disabled persons organisations.

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