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## Working Paper

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# ESRI Working Paper No. 747

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## 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”

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## **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”**

Personal assistance (PA) services have been an evolving part of Irish provision for people with physical and sensory impairments for roughly three decades, but the lack of national standards for allocation, provision or data collection have made it an opaque system characterised by piecemeal or ad hoc local solutions to increasing need. This study approaches the system through the perspective of institutional insiders, eliciting the views and experiences of state and NGO based institutional stakeholders about the PA system and its challenges. A two-step exploratory mixed-method design, incorporating a series of qualitative interviews and a survey of HSE disability managers, provides rich insights into the nature of PA provision in Ireland. The findings illustrate and explore several chronic issues facing the PA system, most notably around under-funding, inadequate administrative data records and variation in allocation and provision across the country.

Keywords: personal assistance, independent living, Ireland, Health Service Executive, United Nations Convention on the Rights of Persons with Disabilities.

### **Introduction**

Article 19 of the Convention on the Right of Persons with Disabilities (CRPD), adopted by the United Nations (UN) in 2006 and ratified by Ireland in 2018, recognises ‘the equal right of all persons with disabilities to live in the community, with choices equal to others’ (United Nations 2006). Current Irish policy is outlined in the National Disability Inclusion Strategy 2017–2021, in which Action 94 ‘aims to reduce the number of people living in congregated settings by at least one-third by 2021 and to ultimately close all congregated settings’ (Department of Justice and Equality, 2017). Personal assistance (PA) services in particular are regarded as an integral support for community living (Mac Domhnaill et al., 2020). PA is regarded in the literature as a ‘leading symbol’ of independent living in practice (Askheim, 2003), and as ‘one of the most significant innovations in disability policy’ (Mladenov, 2019).

For this study, in line with Irish policy, 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' (Buchanan, 2014). It is important to note that the word "employed" is meant here to mean that the personal assistant is directed by the disabled person, not actually employed by them in the usual meaning of the word. The principal forms of personal support services funded by the Irish government are the Home Support Service and PA hours, with the numbers in receipt of these services weighted roughly two to one in favour of home support (Department of Health, 2021). The Home Support Service provides home care, typically understood in Ireland as support at home with cleaning, cooking and other light household tasks that an individual is unable to do due to a disability, although this scope has expanded to include assistance with personal care such as hygiene and dressing (Kiersey and Coleman, 2017). Personal support services, including PA services, are provided primarily to persons with physical and sensory impairments – though there are some people with intellectual disabilities receiving PA. Disabled people over the age of 65 are not eligible for PA in Ireland as they are supposed to transfer into Older Person Services (OPS), which includes home help/home care but not user-led PA (Working Group 1, 2018). However, previous research (Working Group 1, 2018) has suggested that there may be a degree of interchangeability between these two services for disabled people.

Ireland represents an interesting case study for an examination of PA support services. Ireland is regarded by some as historically similar to the UK in terms of disability policy and practice while generally lagging behind in terms of implementation (Fleming, McGilloway and Barry, 2016). Tschanz and Staub (2017), however, place Ireland in an alternative 'Southern European' model of welfare state, which is characterised by a preference for social protection over individual freedom, along with Poland, Luxembourg and southern European countries.

Earlier evidence on the characteristics of PA in Ireland, found that service information is inadequate, the service has become increasingly under-funded, and delivery is area dependent (Buchanan, 2014). As funding has been stretched by more people sharing the same number of hours, Buchanan argues that the scope of PA has narrowed. She suggests that new users, especially, receive fewer hours than established users with similar needs and thus can only cover their basic personal care needs, if that. The HSE's National Service Plan 2020 shows why this is the case: 'Delivery of the planned level of services is dependent on the requirement for all services to manage and prioritise costs within available budgets' (HSE, 2019). While the pool of need grows, the pool of funding has remained largely static, with the

Disability Federation of Ireland arguing that no additional funding was allocated to PA supports between 2008 and 2018 and thus no new hours were created (McCarthy and Toner, 2018). While there have been funding increases since, they are not enough to cover existing demand, either among those currently accessing services who do not have enough PA hours or among those not currently accessing services.

As well as funding, Buchanan (2014) suggests that the situation of PA services entirely within the HSE narrows the scope of PA provision, enshrining a medical model of disability in the fabric of the PA system. Under a social model of disability, the personal care aspects of PA support would be one aspect of a holistic service which would offer independence across the service user's day-to-day life. The DFI has also pointed out that the understanding of PA varies across CHOs, with the service viewed as social support for community participation in some areas, but as a personal care service that is equivalent to the Home Support Service in other areas. Moreover, they note that some who apply for PA are provided with home support instead, perhaps reflecting the lack of a needs-assessment process that is standardised across CHOs. They consider this practice 'deeply problematic' as it obscures any measure of demand, or unmet demand, for PA, with applicants being removed from waiting lists on the basis that they are provided with home support instead (McCarthy and Toner, 2018). An interesting subgroup of PA service users are those who receive Direct Payments from the HSE rather than receiving a fixed number of hours through a service provider. Under the Direct Payment model, the service user receives the funding directly to allocate towards PA hours as they choose. A study of PA service users participating in the Direct Payment model with the support of *Áiseanna Tacaíochta* (an organisation which facilitates Direct Payments and provides guidance and training on using them) found that participants saw this approach as increasing their independence and autonomy, but that it placed a burden on them that may not be appropriate for all PA service users (Keogh & Quinn, 2018). The HSE is currently trialling a Personalised Budget project to expand the Direct Payment model to more users across the country (Department of Health, 2018).

The local context shapes PA provision through historical contingencies, institutional legacies, cultural mores and socioeconomic circumstance, meaning the Irish situation is unique – and, indeed, an outlier in certain senses. Nonetheless, it shares goals and challenges with other countries, particularly those which have similarly witnessed funding for public services stagnating or being cut since the 2008 financial crisis. In Sweden, a country which is often held up as an example of a strong PA system, Thompson and Svaerk (2019) note that

PA provision is intended to create equitable living conditions, increase independence, self-determination and full participation in the society, mirroring the Irish system's aspirations. Mirroring the Irish system's reality, however, while the number who received a PA allowance rose steadily after key legislation was enacted, this 'tapered off from 2009 when economic considerations came into play'. The number of 'basic needs' covered has been reduced, the number of applications for PA allowance that are rejected is increasing and the number of allocated hours is decreasing. Inconsistencies in the allocation of supports have also been noted: while municipalities provide supports for those no longer entitled to the national PA allowance, their policies and budgets vary significantly. A further negative outcome has been the onus now imposed on families of disabled people to supply supports, that is, the re-familialisation of disability support. The international literature shows similar issues elsewhere in the world, from Europe (Mladenov, 2019) to Taiwan (Chou, Chen & Kröger, 2021).

In Ireland, according to the HSE, 1.7 million PA service hours were delivered to 2,552 people in 2020 (HSE, 2020). However, data from 2017 show that 84% of all of those in receipt of a PA service received less than three hours per day on average, with 44% of PA service users in receipt of 42 minutes per day on average (Pringle, 2019). Moreover, there is a crucial lack of evidence on current PA service provision in Ireland. There is little understanding of how eligibility is determined, how PA services are provided, the outcomes of this provision for PA service users and what data are collected on PA applicants and service users. To contribute to a stronger evidence base on the nature and adequacy of these services, this study took a mixed method approach, starting with a set of semi-structured interviews with disability managers in selected HSE areas and among non-statutory providers of services, followed by an online survey with disability managers to capture practices and provision across the country. This paper therefore outlines the institutional perspective on PA provision, while a second phase of the research programme focused on service users' experiences and opinions (Carroll & McCoy, 2022). In this paper, thematic analysis of qualitative interviews alongside descriptive analysis of survey data allows us to address four key research questions:

- (1) How is eligibility for PA services determined and does this vary across regions?
- (2) How are PA services allocated across the country?
- (3) How do key stakeholders perceive the PA system, in terms of the adequacy of provision and responsiveness to need?

(4) Can changes to the PA system be recommended in light of the evidence presented?

## **Methodology**

The most straightforward way to paint a national picture of PA provision and unmet need would be through national level administrative datasets recording the numbers accessing services, the amount of hours provided and the numbers on waiting lists or otherwise experiencing unmet need. Some of these data are recorded systematically at the national level but much of it is not. The HSE records Key Performance Indicators including total numbers in receipt of a PA service and the total number of PA hours delivered. KPI data are broken down at the CHO level, and display significant variation across CHO areas. Some of this variation may be linked to some areas meeting PA candidates' needs through funding allocated to Home Support hours or other supports rather than PA. Whether these (technically) non-PA hours should be considered PA, and whether all hours recorded as PA meet the definition used by this study (and the HSE) is a question we will return to in the discussion. The KPI data does not touch on unmet need, either in terms of inadequate provision for existing PA service users to meet all of their needs or in terms of those who are not currently accessing any services at all.

The National Ability Support System database (NASS) aims to capture data around PA hours received as well as more detailed, individual-level data on demographics, disability type and unmet need, but at present its coverage of PA is partial – it is hoped that this coverage will continue to grow over the next few years. Even when coverage does extend the NASS will only include those accessing services, and so will not touch on unmet needs among those not accessing any services at all.

Overall, the available administrative datasets give some sense of the outline of PA provision in Ireland, but currently provide little insight beyond the raw numbers of PA service users and total hours allocated. In order to understand the nuances of the system and to get at challenges unrecorded in KPI or NASS data it is necessary to engage with key stakeholders and elicit their perspective on the PA system.

This study adopts a sequential exploratory mixed-method design, drawing on qualitative and quantitative research methods. A mixed methods study involves the collection or analysis of both quantitative and/or qualitative data in a single study in which the data are collected concurrently or sequentially, are given a priority, and involve the integration of the data at one or more stages in the process of research (Creswell, Plano Clark, Gutmann &



Hanson, 2003, p.212). Given the lack of prior knowledge in this area, we take a sequential exploratory mixed method approach. This comprises a two-stage design in which qualitative interviews are undertaken and, in the next stage, complemented with a survey with a broader cohort of disability managers operating across the Health Service Executive (HSE) (Creswell et al., 2003). Such mixed methods approaches have gained growing popularity in disability research, allowing the exploration of provision or experience at an overall level, and differential experience among sub-groups or areas (see, for example, Kroll, Neary and Miller, 2012). Drawing on a theoretical sampling frame of geographical regions and urban/rural areas, a number of HSE disability managers were identified for interview. Three in-depth online interviews were completed late in 2020, one from Munster, one from Connacht and one from Ulster. All three are from rural areas. In order to gain a richer understanding of the PA landscape, a similar number of interviews were conducted among private providers, some from for-profit organisations and some from “Section 39 organisations”, who have varying roles in providing PA supports to people in the community. Section 39 organisations are non-profit bodies funded by the government to provide healthcare, elderly, youth, substance abuse, suicide prevention, social inclusion, education, community development and many other services in communities across the State. In total, four such interviews were undertaken, also online or over the phone. All interviews were audio recorded with the consent of participants and analysed. Table 1 details the characteristics of the seven interviewees forming the first phase of this study. Achieving buy-in from potential interviewees was challenging in the context of the COVID-19 pandemic, but the seven interviews provided a valuable insight into PA provision across the country.

Table 1 Interviews with key stakeholders

<b>Country</b>	<b>Organisation</b>	<b>Region</b>	<b>Urban/Rural</b>
Interviewee 1	HSE	Munster	Rural
Interviewee 2	HSE	Ulster	Rural
Interviewee 3	HSE	Connacht	Rural
Interviewee 4	Non-Profit Section 39 Provider	National	
Interviewee 5	Non-Profit Section 39 Provider	National	

Interviewee 6	For Profit Provider	Connacht/Leinster	Rural
Interviewee 7	Non-Profit Section 39 Provider	National	

Source: *Qualitative Interviews*

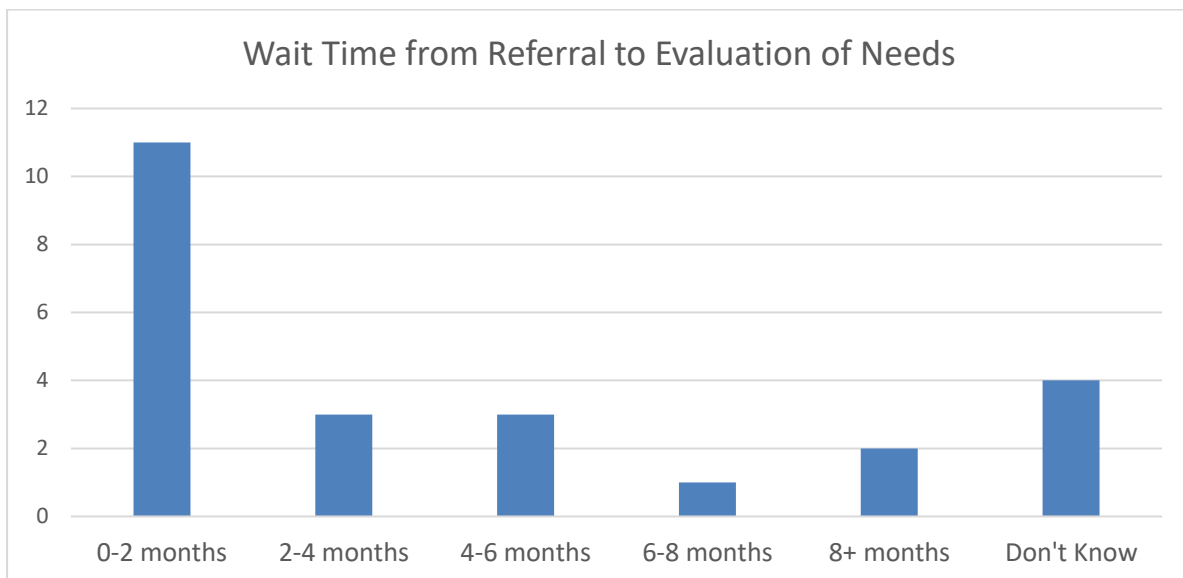
The interviews also served to guide in the development of an online survey of disability service managers across the HSE. Key issues emerging in the qualitative interviews informed both the areas to be addressed in the survey and the way in which questions and response categories were framed. Following extensive consultation with the funders of the study, the National Disability Authority, and key stakeholders overseeing the study, the final online survey comprised 28 questions (see Appendix 1). The survey included questions on the types of PA supports provided, the timing and nature of the needs assessment process, the main providers of PA services, the process for the allocation of services, perceptions of the adequacy of provision, challenges in meeting PA service users' needs and changes in the PA system they would like to see. The survey was disseminated through the central HSE disability service to the HSE's 32 disability managers, each of whom oversees all disability supports within a specific geographical area. In total, 25 responses were received in April 2021 from disability managers across all but one of the 9 Community Healthcare Organisations (CHOs). The 9 CHOs are all operated by the HSE, with the aim of making it easier for people to access local services, improving management and accountability, and allowing stronger local decision-making. CHOs comprise community healthcare services outside of acute hospitals, such as primary care, social care, mental health, and other health and well-being services. Social care services encompass those for older people and disabled people. Their establishment follows the publication of the report and recommendations of the Integrated Service Area review group in October 2014. The survey respondents are treated as independent respondents for the purposes of this paper, and while some were employed in the same CHO region, the responses confirm that practices and provision within, as well as across, these broader regions are highly variable. The respondents are employed across a diversity of areas, including those comprising (mostly) urban areas (n=3), a mixture of urban and rural areas (n=9) and those which were (mostly) rural (n=13).

## Results

The findings of this study paint a broad view of the PA system in Ireland. They are laid out here in three sections, covering the PA allocation process, PA provision and perceptions of the PA system. The qualitative and quantitative findings are both woven across the three sections to provide a rich and nuanced insight into PA in Ireland from the perspective of key institutional stakeholders.

### ***PA Allocation Process***

The first phase of the PA process is the allocation of hours, typically involving an assessment or evaluation of needs and a contracting process with a service provider or multiple service providers. In Ireland, the PA allocation process begins with a referral, almost always from a GP, hospital or other medical provider, thus linking PA to a medical model of disability from initial engagement with the system onwards. From this referral, most but not all survey respondents (88%) indicated that PA service users received an evaluation of needs before PA provision began. Figure 1 below shows responses about the typical wait time between referral and evaluation of needs and the wide variation across CHOs, with almost half of the responses indicating 0-2 months but one response indicating ‘24 months plus’.



*Figure 1 Wait Time from Referral to Evaluation of Needs*

Three-quarters of respondents indicated that there was an emergency process for individuals with urgent needs, which was typically used ‘as and when needed on individual case by case basis’. Here again, there was variation in approach, with the emergency process described as being used ‘rarely’, ‘sometimes’ and ‘very frequently’. One respondent also

pointed out that the emergency process ‘causes stress on other services being provided due to funding limitations’.

The evaluation process was generally conducted by a multi-disciplinary team involving HSE Disability Services staff, occupational therapists, public health nurses, social workers and service providers. Again, this varied across areas and even within areas, ‘depending on the needs of the person. The appropriate disciplines are involved and all feed into the process.’ Figure 2 shows the different needs included in the evaluation of need process, reflecting a prioritisation of basic care needs (ADLs) over wider independence needs.

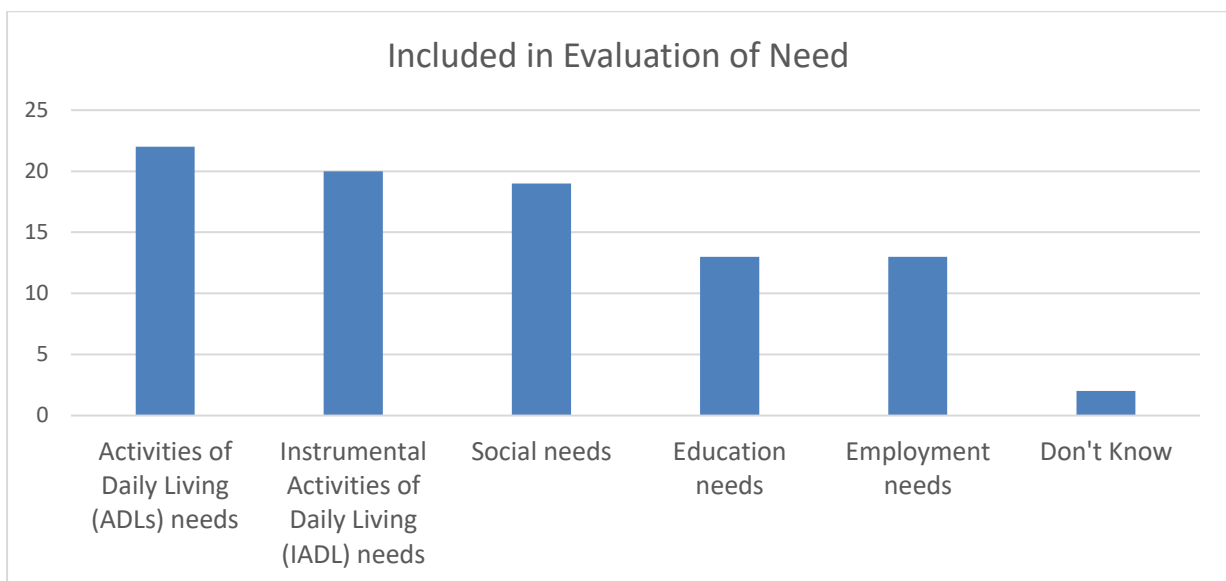


Figure 2 Evaluation of Need

In response to an open-ended question about how the service user’s own preferences were considered during the evaluation process, almost three-quarters of responses referred to a ‘person-centred’ or ‘user-led’ approach. Just 2 responses stated that this was not the case in their area, as ‘support is based on availability of staff rather than the person’s preferences.’

A total of 57% of respondents indicated that a standardised assessment tool was used for the evaluation, with 30% indicating that they did not know and 13% indicating that no such tool was used. The standardised tool used was described by several responses as one specific to their area and designed “in-house”, while only 2 responses mentioned standardised scales described in the literature. In the qualitative interviews, the assessment of need carried out was different in each of the three HSE areas featured. In one, the assessments were

carried out by a Section 39 body rather than by the HSE directly. In the other two, the HSE carried out the assessment based on a locally developed instrument. While these instruments were informed by best practice in the field, they were still ultimately unique to the local area.

One of the Section 39 representatives interviewed for this project carries out its own assessment of needs with any new service user allocated hours with them. This generally takes place once the allocation of hours has been completed, and is used to allow the service user to determine how they would like to distribute these hours. As such, it enshrines a user-led service, but one constrained by resource considerations in the allocation process.

Half of the responses described a routine, annual re-evaluation of need, while 45% described re-evaluation as only taking place when the individual's circumstances or capacity changed (only one respondent answered that they did not know). One respondent said that they 'ideally would like to re-evaluate yearly however do not have the capacity to do so.'

Overall, the allocation phase showed wide variation across areas in terms of time taken, instruments used, protocols for urgent cases, the role of the service user's preferences and the regularity of re-evaluation of needs after the initial allocation.

### ***PA Provision***

Provision of PA services was similarly uneven across different areas. Figure 3 below shows which supports are provided to PA service users. As with the evaluation, there is a clear prioritisation of support for ADL needs, with less support provided in other areas of the service user's life. For each of the other types of support included in the question, the most common answer was that it was provided to some in receipt of PA services.

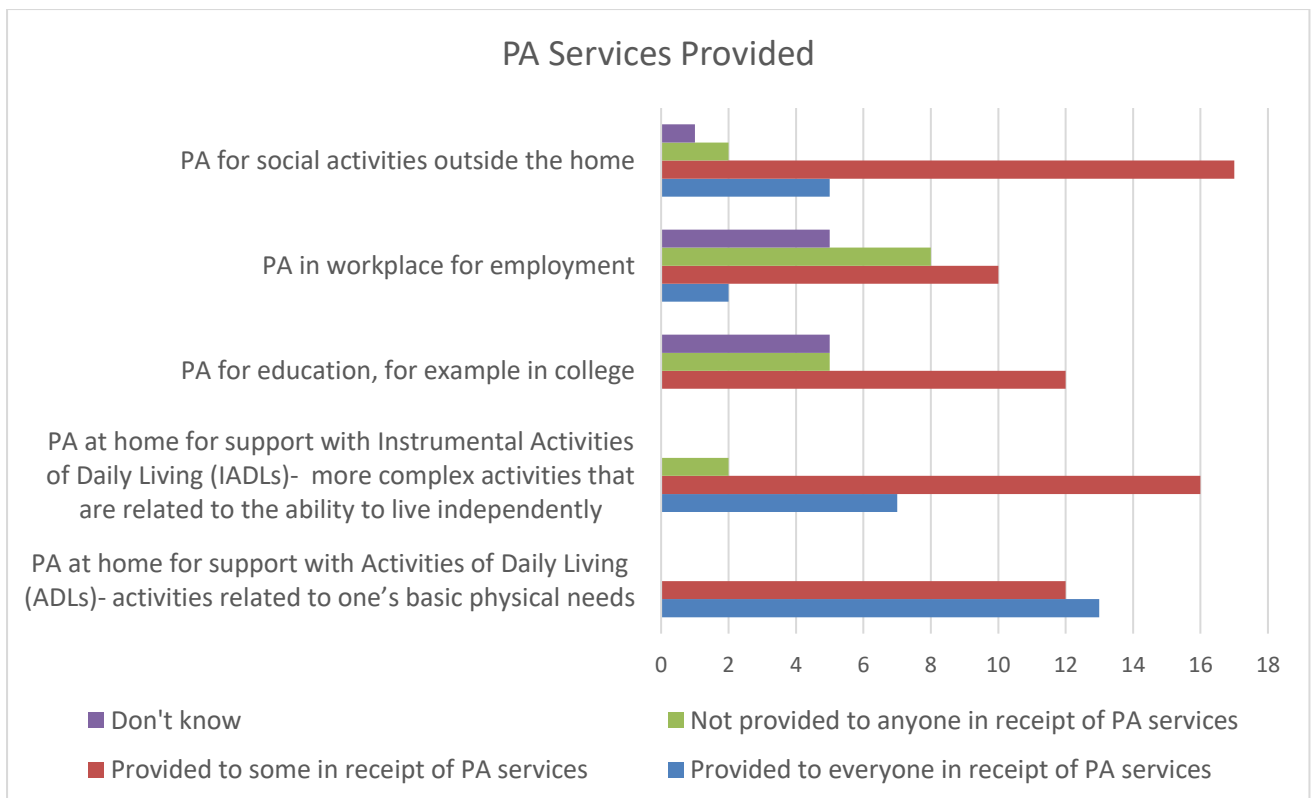


Figure 3 Types of PA services provided

The qualitative interviews complicate this picture. All of the HSE interviewees (as well as interviewees from Section 39 bodies) felt that the PA hours allocated by the HSE were all targeted at support for Activities of Daily Living (ADL). This focus, however, was explicitly described as too narrow by two of the HSE interviewees and by each of the Section 39 bodies interviewed. In particular, social supports were pointed to as an area where PA service users had a need which was not being met, or was being met on an ad hoc, unfunded basis through community and voluntary organisations. None of the interviewees reported providing supports for employment among PA service users, while they suggested that supports in education are handled by educational institutions themselves rather than by the HSE. This divergence between the qualitative and quantitative data may be a result of variation across areas, or it may reflect different approaches to answering questions in an interview rather than a survey. It is a key question arising from this research, and one which will be considered in the conclusion to this paper.

While the HSE funds PA, it does not directly provide it, instead working with a range of service providers across the country. Figure 4 shows how service providers are selected for each case, with an emphasis on service user wishes and the available providers within the CHO. The type of impairment or disability of the service user was less frequently seen as very important, but still very widely factored into the decision. In many cases the HSE has a

block grant of hours for specific service providers, and this was also an important factor in the selection. The overall lack of emphasis on competitive tendering is of interest considering the funding constraints facing PA services.

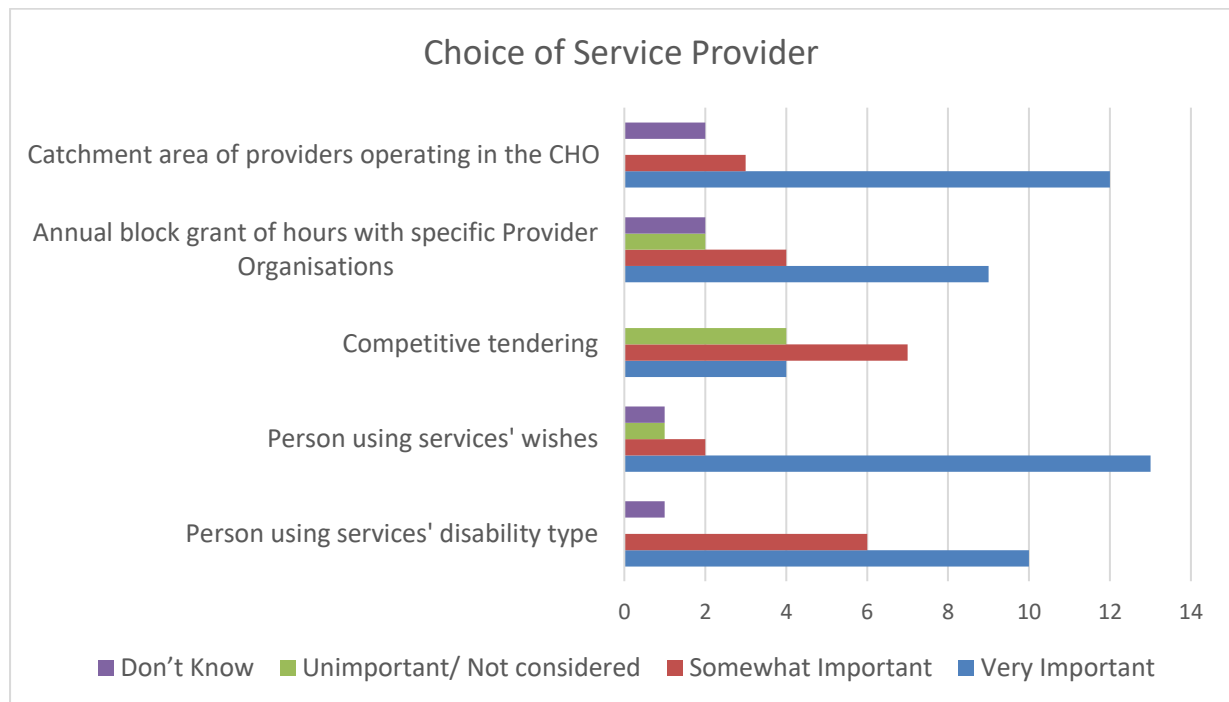


Figure 4 Choice of Service Provider

The quantitative and qualitative data show significant variation in the presence and provision share of service providers across the country. In the qualitative interviews, the exact distribution of PA hours varied significantly across the areas covered in this sample. In one, a single Section-39 body provided “90%” of the hours, as well as completing the assessment of needs. The rest of the hours were beyond the capacity of the Section-39 body to meet, and these were put to tender among other agencies – but only after being refused by the large provider.

In the other two areas a much wider spread of bodies were used – one had service level agreements with 16 agencies. In each, a block grant was used each year with specific organisations, generally non-profit bodies like the Irish Wheelchair Association or regional Centres for Independent Living, and any further hours required were put to tender. These tendered hours were generally awarded to private, for-profit organisations. A survey question about the largest service providers in the respondent’s area generated an equally varied mix of national and regional bodies and non-profit and for-profit organisations. The for-profit provider interviewed was somewhat critical of the allocation process, feeling that the HSE

relied on them to cover excess hours and emergency cases which non-profit organisations could not take on but would not include them in the allocation of more regular PA hours.

As well as non-profit providers and for-profit providers, there are a small number of organisations which support PA service users in taking total control over the sourcing of their hours. While the HSE Assessment of Need still determines the number of hours available to them, these PA service users are directly allocated the funds for the hours without the involvement of a third party. The PA service users are then responsible for hiring staff to complete the hours, giving them full autonomy in who carries out the PA, what the PA actually entails and when it is scheduled. However, this model comes with arduous responsibilities and is not suitable for everyone. The service user must register their own company to receive the funds from the HSE and are completely responsible for hiring, payroll, tax and compliance with legal standards. Managing all of this requires training and a significant amount of time each week. Interviewee 5 suggested that learning from the Swedish or UK system could remove the need to register as a company, but believed that this model would always be more labour intensive than the provision of hours through a Section 39 body.

Figure 5 shows the typical time taken between the acceptance of a referral and the start of PA provision. Complicating the responses, however, is the fact that differing definitions may be in use around when the process begins. One respondent marked the typical wait time as “0-2 months”, but also noted in the accompanying open-ended answer section that “[w]hilst referrals are accepted onto a waiting list the above answers when hours are allocated.” Another respondent chose “Varies widely”, and explained that

*We can only provide support if we have the hours available. We have to recycle hours as we do not get yearly increases. In essence this means one has to leave the service (usually a death) to provide service to a client requiring it. We do not have any deaths some years so a waiting list exists for services which is reviewed and prioritised on a monthly basis*

This would suggest that the times displayed in Figure 5 reflect the time taken to evaluate new users, contract a service provider and commence provision, but do not reflect the fact that there may be a significant waiting period before this process can begin.



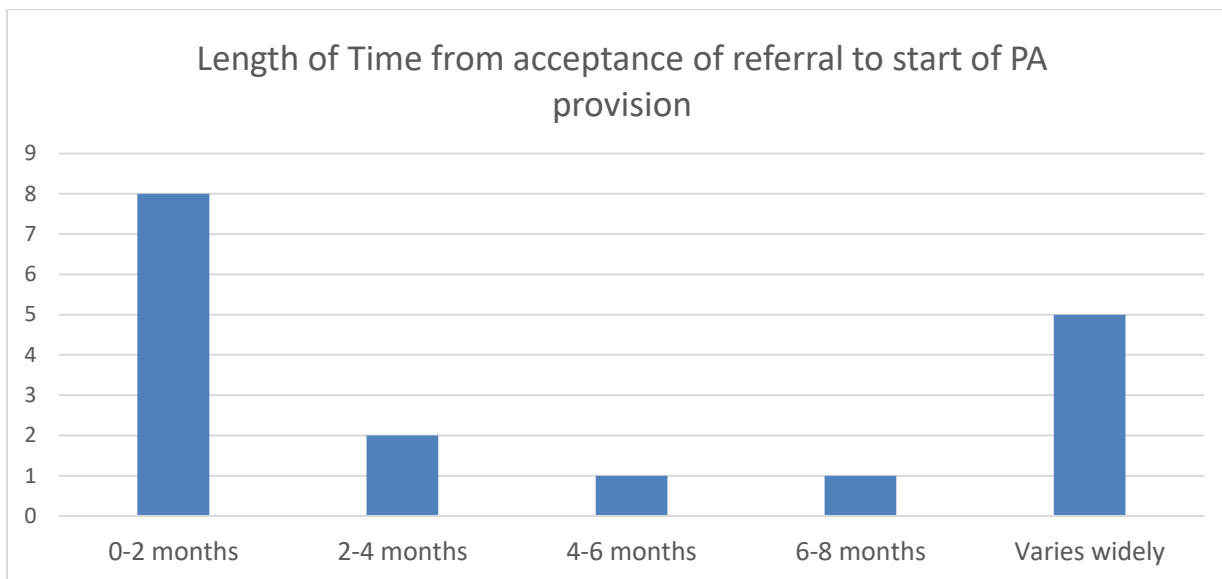


Figure 5 Length of Time from Acceptance of Referral to Start of PA Provision

Respondents were also asked what happens if resources are not available to provide PA supports to an accepted referral. The responses revealed a variety of approaches, from waiting lists to providing as many hours as possible even if these hours were not sufficient to meet the user’s needs to passing the referral to another branch of the HSE such as residential care or leaving the user dependent on family supports. One response noted that resources were linked to a referral in their area, and thus nobody received a referral until resources were available to provide hours for them.

Another issue arising from the qualitative interviews was the use of other supports for PA service users. Respondents were asked which other services users might typically be signposted towards, alongside or instead of PA. Responses highlighted some complementary services, such as day services, transport support and multi-disciplinary team referrals. These were seen as ways to “broaden the resources available to the person.” However, other responses mention allocating home support or older persons services due to “inadequate or no PA provision” or because the PA “budget [is] not sufficient.”

A final issue around provision and allocation related to the current age limit of 65 for PA supports. This limit is generally treated as an age limit for allocation rather than provision, with almost three quarters of survey respondents indicating that they provided PA services to over 65s in their area and a further fifth stating that they did not know. In the qualitative interviews, one HSE interviewee and one Section 39 representative raised concerns about the appropriateness of this age limit. In particular, they were concerned about the loss of autonomy that came with the move to the Older Person Services (OPS), where provision is HSE-led rather than service user-led. The HSE interviewee reported having

discussions on PA service users reaching the age limit which led to some being kept on the PA system where they felt it was more suited to their needs. New allocation for over-65s, however, was not an option even in cases where it might be better suited to their needs than OPS.

Overall, the quantitative and qualitative data suggest that PA provision in Ireland is a largely ad hoc affair built on local features like the presence or absence of specific non-profit organisations and institutions rather than a national strategy or standardised approach.

### ***Perceptions of the PA system***

As key stakeholders in the PA system, questions around the perceptions and opinions of respondents were also included in this study. When asked about the effectiveness of the PA system in providing “at least some PA hours to all who need PA in the area”, respondents were evenly split between agreeing and disagreeing, as displayed in Figure 6 below.

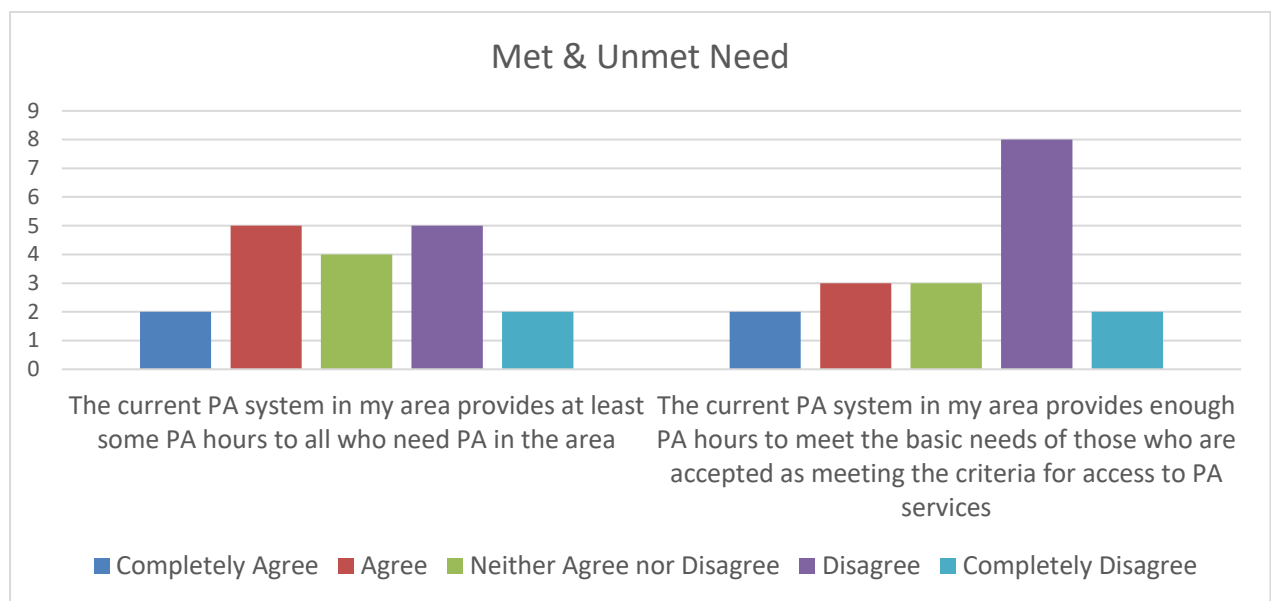


Figure 6 Met & Unmet Need

When asked about whether the PA system provides “enough PA hours to meet the basic needs of those who are accepted as meeting the criteria for access to PA services”, however, 8 out of 18 respondents disagreed and 2 completely disagreed. In an open-ended question about which needs were not being met, some answers referred to issues across “all of the identified needs” while others singled out specific needs including “Social supports, community access, independent living (specifically suitable housing), access to education and

training courses, support to access work”. Issues around those not receiving any support were also flagged:

*The basic needs of all service users that have PA hours in place are being met. However, we have approx. 115 people on our waiting list for hours. We have accepted these people as they meet the criteria for supports but we don't have the resources to provide the services.*

When asked about their perception of the challenges facing the PA system, “funding” was labelled an “extreme challenge” by 10/14, a significant challenge by 3/14 and a slight challenge by 1/14. Figure 7 shows this and other results, with the presence of Personal Assistants to provide PA and, to a lesser extent, the presence and capacity of provider organisations and of HSE staff in the area also widely identified as slight or significant issues.

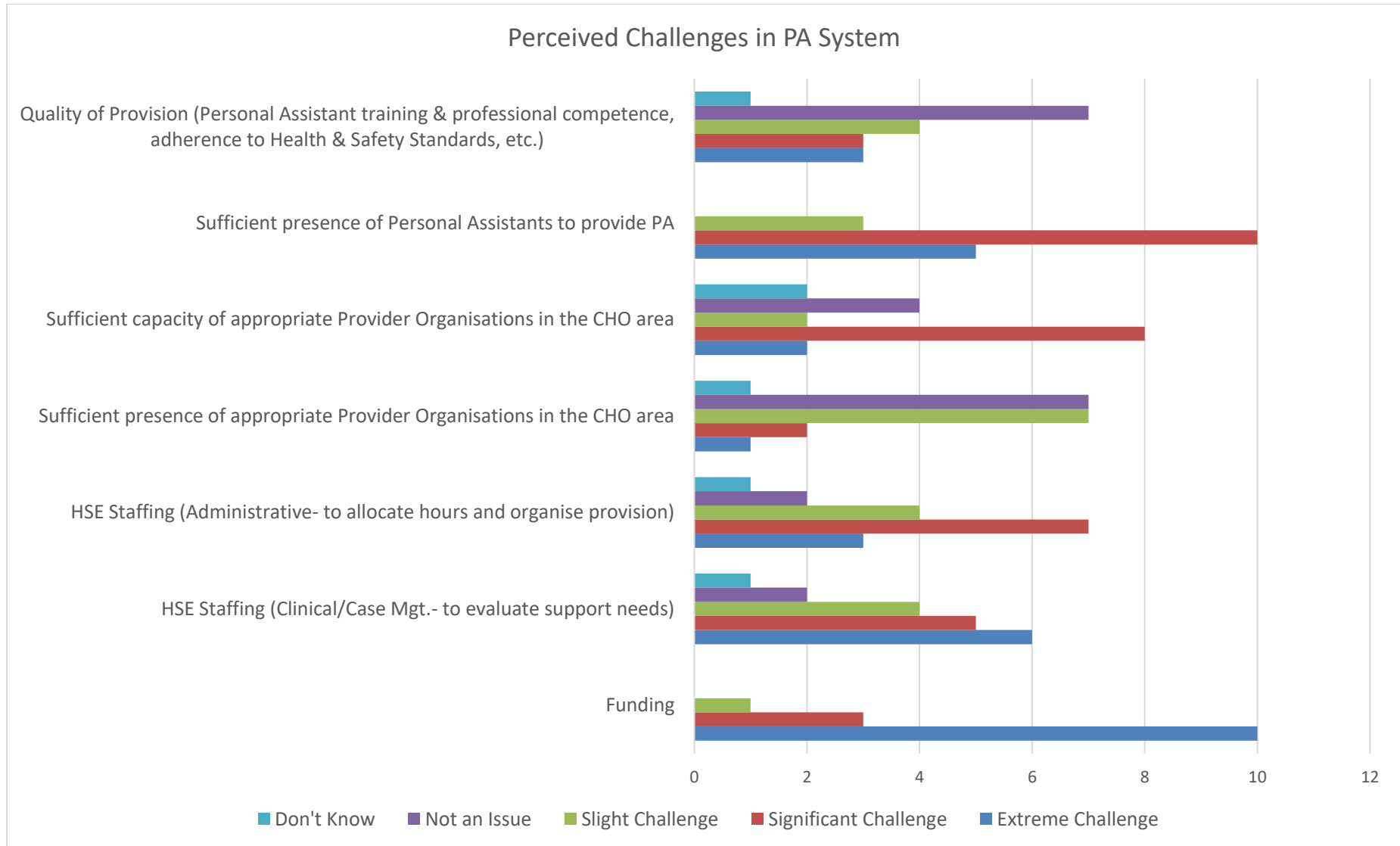


Figure 7 Perceived Challenges in PA System

Responses to an open-ended ‘Other’ section included a reiteration of the challenges posed by inadequate funding, several mentions of the difficulties in recruiting and retaining personal assistants, concerns about quality assurance and perceptions that there can be “a huge challenge in getting providers to support complex cases”. One respondent who oversaw a mixed rural and urban area noted that there were far greater issues facing rural areas in terms of capacity and presence of service providers within their area.

The difficulty of recruiting and retaining staff to carry out PA hours was remarked on by one HSE interviewee and three Section 39 representatives in the qualitative interviews. In the case of the HSE interviewee, two issues in particular were raised. Firstly, their area included remote rural areas, and finding any staff to cover these was challenging due to the small and sparse population:

*Depending on where the person lives, depending on what’s required, if it’s a really big package it can be challenging, if it’s a remote area... the providers struggle to find carers.*

Secondly, achieving continuity in staff providing PA to service users was difficult as the Section 39 bodies they worked with struggled to retain staff. The main reason given for this was the relatively uncompetitive wages and career structure they offered compared to work in HSE care facilities. The section 39 representatives offered a further perspective on the difficulties of retention. While the flexibility of the Personal Assistant role was a positive aspect of the job for many, the fact that PAs were not paid for the time spent in transport was highlighted as an issue for situations where service users wanted only one or two PA hours together.

A final open-ended survey question provided a chance for respondents to make additional comments on the PA system. The responses were coded into four categories, focusing on how the system could be improved by greater funding, more effective organisation, a stronger emphasis on fairness and better working conditions for PAs. Table 2 below shows the key responses from each category.

Table 2 HSE Disability Managers’ additional comments

Code	Example 1	Example 2
<i>Funding</i>	“Personal Assistant Service should be funded to a higher level to enable adequate hours be put in place so that the	“Very challenging area that requires more funding, more intense focus and oversight.”

	person with the disability can live their best life independently.”	
<i>Organisation</i>	“Yes, the PA service provides an invaluable service for a considerably low budget in comparison to other disability services. If the allocation of funding and responses to business cases was improved and managed in a manner that was proactive rather than reactive it would give a major opportunity for a growth in service provision in a timely manner. 'A little goes a long way' describes the invaluable PA support. The introduction of standards and HIQA oversight would be a beneficial move to ensuring the growth and development of this area of service provision.”	“Personalised Budget system and mechanisms to support it should be greatly enhanced and promoted. Additional case managers to monitor quality and value for money.”
<i>Fairness</i>	“I would like to see a more structured approach on how service users are allocated hours. It seems that some service users can be allocated more hours than others for the same tasks and it is unclear why this happens.”	“Political representation for specific cases should not be allowed.”
<i>PA Conditions</i>	“Challenge is funding & PAs having viable employment. Good contracts and progression in the sector.”	

Source: HSE Disability Manager Survey

In relation to organisation, three interviewees (Interviewee 4, 6 and 7, all non-HSE) felt that there was a need for clearer standards in the field, mainly in relation to the standard of care required and the training PAs needed to meet this. The interviewees diverged on what these standards should look like and how they should be enforced, however. Interviewee 6 wanted the Health Information and Quality Authority (HIQA) to play a more active role in setting standards and auditing providers, while interviewee 7 felt that HIQA involvement would bring too much bureaucracy and place too large a burden on providers.

There were some shared perceptions of the challenges and strengths of the PA system across most or all respondents and interviewees, particularly in relation to the need for greater funding for PA and better working conditions for PAs as well as around a widely shared belief that PA was at present able to meet only the most basic needs of those accepted for referral to the system. There was much more divergence on deeper questions of how to improve the system, and the conclusion will contextualise some of these debates in terms of what they mean for PA reform in Ireland.

## **Conclusion**

The findings of this study suggest that the problems facing the PA system described by Buchanan in 2014 remain largely unsolved, with under-funding and uneven provision across the country emerging as particular issues. The qualitative interviews suggest increasing pressure on the system as the number of people needing support increases without a corresponding increase in funding, and a further reduction in focus to exclude all but the most basic and urgent personal care needs. The quantitative evidence points to a wider breadth of PA supports being provided to at least some PA service users – further research is needed to determine where, for whom and to what extent this is the case. The data also suggest that new users remain likely to receive fewer hours than long-term users with similar needs, while waiting lists to receive even these hours can stretch into periods of years. In terms of evaluating and auditing the system, some areas appear to have no waiting lists not because there is nobody waiting but because there is no list, with referrals simply not accepted until funding is available.

As long as PA provision remains constrained by a fixed and inadequate budget it is difficult to see these issues being resolved, or even significantly ameliorated.

Establishing a legal entitlement to services based on a uniform and transparent assessment process appears to be the most effective way to ensure fairness and adequate provision across the country, but it would come with significant costs and disrupt budgeting by making required funding proportional to recognised need rather than the current system of forcing recognised need to be proportional to available funding.

Slasberg and Beresford (2019) suggest a compromise approach wherein assessment is based on needs and provision on budgets, keeping expenditure under the state's control while also formally recording the level of unmet assessed need and projecting the cost of meeting it. A statutory scheme for the financing and regulation of home support services currently in development by the Department of Health seeks to reach such a compromise for guaranteed levels of Home Support, but it is not clear as of yet where PA will fit into this scheme (Walsh & Lyons, 2021).

A Capacity Review of Disability Social Care Demand which seeks to estimate capacity requirements up to 2032 provides projections for the increased funding the PA system will require over the next decade based on increasing demographic demand and the need to meet currently existing needs among underserved service users and those waiting for or otherwise in need of PA hours (Department of Health, 2021). It also

acknowledges that ‘data on unmet need has not been systematically recorded, given the fixed number of service hours available to deploy, but there are signs it is substantial.’ (Department of Health, 2021, p. 120) Recording that need may prove a vital spur to eventually meeting it, and could thus be considered a prerequisite of effective reform. Establishing a uniform approach to accepting referrals and assigning people to waiting lists would allow these data to be collected at the national level, and waiting list size could be incorporated into the existing PA KPIs and reported on quarterly. Furthermore, a standard national approach to the allocation process from referral through assessment to the start of provision would allow for current best practice across Ireland to be synthesised and made into a benchmark for all CHOs to meet. Adopting such a standard national approach would also be an opportunity to establish a clear delineation between PA and other supports including Home Support and Older Persons Support, ensuring that the right type of support is provided and allowing better tracking of unmet PA need.

While tracking and eventually meeting the pool of unmet need among those currently not availing of any PA supports is a daunting task, it is at least clear what needs to be done. The other side of unmet need is in some ways a thornier issue, one which poses the question of what meeting a disabled person’s PA needs actually looks like. What does it mean to ‘enable [the service user] to live an independent life’? A medical model of disability, such as that currently guiding PA provision, offers standardised tools to assess and quantify an individual’s personal care needs, but the literature and Irish Disabled Person’s Organisations (DPOs) call for an understanding of PA that goes far beyond these basic needs. A social model of disability, meanwhile, locates the issues facing disabled people not in their illnesses or conditions but in the way society is organised without regard to their capacities or needs. Approaching the question of what PA should look like through a social lens demands that we think about how services can be provided to ensure that disabled people are able to engage as fully with the world as anyone else. As well as meeting basic personal care needs, this model of PA provision would ensure disabled people could participate fully and equally in education, employment and the public sphere as well as in social activities.

While the institutional perspectives captured in this study provide a vital insight into the system and the challenges facing it, they do not provide anything like a complete picture. In particular, the voices and experiences of PA service users must play a central role in any reform of the PA system. Irish history includes many instances of state and other institutional decision-making about service provision without



consideration of the needs, experiences or opinions of those receiving services. Decades of organisation and advocacy from DPOs and a greater commitment to consultation among state bodies are challenging the balance of power and our research is guided by this movement. This research programme also included a large-scale study of the experiences and opinions of Irish PA service users, the results of which complement, and in many ways challenge, the results of this study and contribute to a more holistic understanding of the PA system, providing a stronger platform from which to make much needed policy recommendations (Carroll & McCoy, 2022). Bearing in mind the ultimate goal of guaranteeing ‘the equal right of all persons with disabilities to live in the community, with choices equal to others’ (United Nations 2006), this research further explores how far from this goal we are and grapple with what it might look like to reach it.

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