

‘To live as others do’

The case for regulation of PA services in Ireland.

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Introduction

The landscape of home care in Ireland is diverse, encompassing home support services provided by the HSE, voluntary organisations and private home care companies; as well as Personal Assistants (PA) employed through voluntary agencies, private home care companies or directly by the client.

Personal assistance is commonly regarded as “one of the most significant innovations in disability policy over the last several decades” and is central to Ireland’s deinstitutionalisation strategy that has brought closure to congregated settings and the expansion of disability supports through community-based services (HSE, 2011). In 2024, the HSE will fund the delivery of 1.85 million PA hours to adults with a physical and/or sensory disability and 3.48 million home support hours to persons with a disability under the age of 65 (HSE, 2024).

Dovida, a provider of home support and personal assistance services, welcomes the forthcoming regulation of home support providers. However, the proposed Health (Amendment) (Licencing of Professional Home Support Providers) Bill 2024 has brought to light significant concerns regarding the exclusion of PA services from regulation. While the Bill aims to regulate home support providers, the exclusion of PA services, which are essential to support the independent living of individuals with disabilities, creates a potential gap in safeguarding the rights and wellbeing of this, often vulnerable, population, as well as creating fragmentation within the home care sector.

This position paper argues that PA services must be included in the forthcoming regulatory framework to ensure consistent standards of care, protect those supported, and uphold fairness within the industry.



Definition of a PA service

The urgent need for the Department of Health and HSE to define PA services was identified ten years ago in the Buchanan (2014) report published by the Disability Federation of Ireland and again by Carroll and McCoy (2022), yet ongoing discussion around the Health (Amendment) (Licencing of Professional Home Support Providers) Bill during the Joint Committee on Health Debate in June 2024 as part of the pre-legislative scrutiny, highlighted the absence of a clear, legal definition of PA services.

Internationally, PA services are defined in different ways and in recognition of this Nally et al (2022) present a working definition of a PA as a “social service, not bound to a particular setting such as home, place of work, or education, that has the option of an individual budget to facilitate a person to undertake the activities of daily living”. Essentially, PA services enable individuals with disabilities, to live more independent lives and participate fully in community life, or as they say so simply in Sweden “to give users the possibility to ‘live as others do’ (Act 1993: 387, §5; Act 1993: 389)” (Roos, 2009). They are directly linked to the principles outlined in Article 19 of the United Nations Convention on the Right of Persons with Disabilities (UNCRPD), which recognises “the equal right of all persons with disabilities to live in the community, with choices equal to others” (UN General Assembly, 2007).

In Ireland, PA services are provided to some adults, under 65¹ years of age, with physical and sensory disabilities. Buchanan’s (2014) definition of a personal assistant is often cited, which Carroll et al. (2023) notes is in line with Irish policy.

“a personal assistant is defined as someone ‘employed’² by the person with a disability to enable them to live an independent life. This personal assistant provides assistance at the discretion and direction of the person with disability, thus promoting choice and control for the person with the disability to live independently”. (Buchanan, 2014)

Indeed, this definition was included in the National Physical and Sensory Disability Database and features as the definition of a PA on the Disability Composite Schedules published in 2024 by the HSE.

A personal assistance review group is currently working on an agreed definition of a PA and it is suggested that without such a definition, regulation of the service would be “difficult” (Larthwell in Joint Committee on Health Debate, 2024). This, coupled with the view that PA services are delivered primarily outside of the home, and therefore outside of the scope of home support, appear to be the two main reasons for the non-inclusion of PA services in the forthcoming licencing of professional home support provider’s bill (Joint Committee on Health Debate, 2024).

¹ The service is not available to those over 65 years of age and the denial of funding for a PA to live an independent life on the basis of age is inherently ageist, as it discriminates based on age and unjustly assumes that older people do not require or deserve the same level of personalised care and support as younger individuals.

² NB employed in this context means directed by as opposed to technically employed.

Lack of definition is not a valid reason against regulation

The ambiguity around an accepted definition of PA services complicates the regulatory process but should not be a reason to delay the inclusion of PA services within the legislative framework. Regulations do not require a single, narrow definition of a service. They are designed to be flexible, accommodating a variety of service types and levels of care to meet the needs of people using the service, in line with the service's statement of purpose. Any regulatory framework is designed to set minimum standards and requirements that apply regardless of the specific tasks performed. So, even if PA services vary from client to client, there are core competencies and standards that can and should be regulated.

These include safeguarding, adherence to ethical guidelines, training and maintaining client dignity and rights. The regulatory framework needs to focus on these essential elements rather than requiring a rigid definition of every possible PA task. Essentially the regulations establish a baseline standard for what constitutes safe and acceptable care in any context.

This would ensure that all PAs, regardless of the specific nature of their duties, meet the minimum requirements for training, conduct and client interaction. In fact, regulation could actually help to create a more standardised definition of what constitutes a PA service by identifying key responsibilities, competencies and expectations. This would provide clarity for clients, families and funders and ensure all PAs understand the scope and limits of their role.

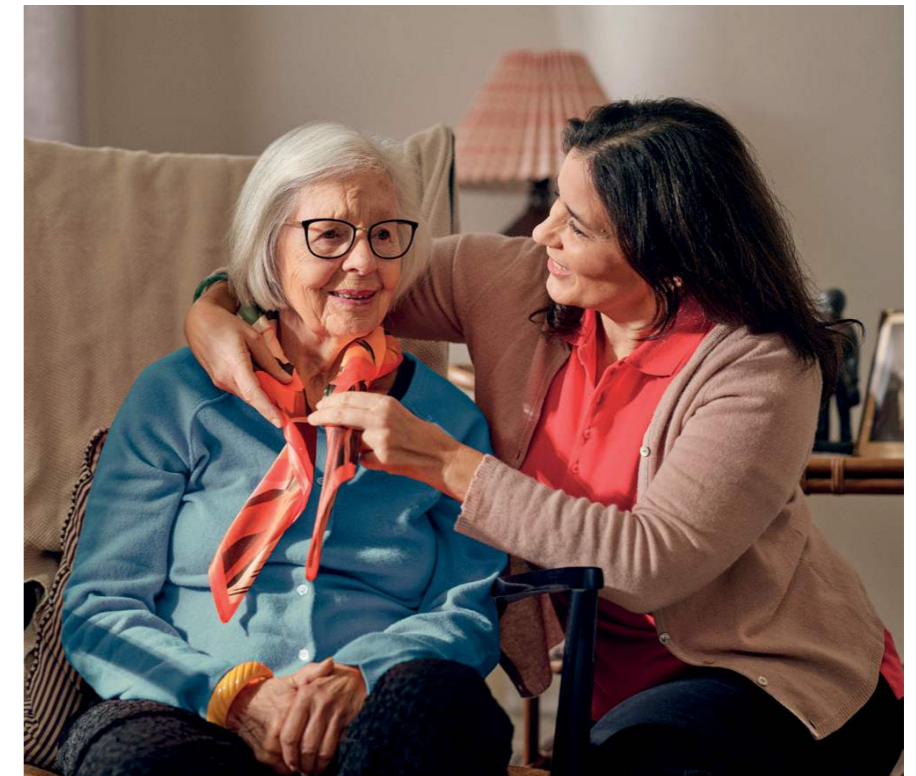
The primary purpose of regulation is protecting clients from potential harm and to ensure quality care. Arguing against regulation due to lack of definition, overlooks the fact that many people with a disability are vulnerable and do need protection. Without regulation, there is a higher risk of substandard care, abuse or neglect, particularly for those who may be unable to advocate for themselves.

Regulation provides a formal mechanism for accountability and recourse if a PA fails to provide adequate care or engages misconduct. This protection is critical, regardless of the specific nature of the PA's duties.



Regulation of the provider is different to regulation of a profession

In the recent HRB report by Murphy et al (2022) that reviewed the role, function and supply of home care workers including PAs in four countries, they noted that in Germany PAs are not required to have qualifications in health and social care and on this basis "they cannot be regulated." Likewise in Scotland, PAs are unregulated and not required to possess a particular health or social care qualification, despite their tasks including supporting activities of family living including personal care and household management. However, the Scottish Social Services Council refers to PAs needing to have the important skills of empathy, flexibility and creativity and they are expected to meet the Scottish Social Services Council Codes of Practice, although they are not required to register with the Council. In the future there will be a requirement for PAs who are not family members of the client to complete police vetting.



Currently, there is no formal supervision or complaint mechanism for PA services in Scotland. Similarly, in Sweden there are no legislative requirements regarding regulation and qualifications of PAs, however, where they are employed directly by the client, a union agreement mandates the client can determine the qualifications required to meet their needs and where employed by an agency, a separate union agreement requires the worker to have completed school and completed a higher vocational education course (Murphy et al., 2022). The National Board of Health and Welfare is responsible for the monitoring and supervision of PA services in Sweden and, whilst they advise and guide and inspect failings, Murphy et al. note there was a lack of detail regarding how this is done. In Sweden it is considered important for the worker to have relational competence and social skills "because the relationship between user and assistant is 'so close and in many ways intimate'" (Murphy et al., 2022). Surely such intimacy requires regulation to ensure that trust, safety and quality care are consistently maintained, protecting individuals from potential abuse or neglect?

We consider that Murphy et al's (2022) statement that PAs cannot be regulated due to a lack of qualification fails to recognise the fundamental difference between regulating a profession and regulating a service provider. We accept that some PAs are employed directly by the person who requires them, and in some cases will be their family member or friend and, therefore will fall outside of the proposed home support provider licencing arrangements.

However, in many cases, PAs are not employed directly by the individual and are sourced and reimbursed by a third party, which is often a Section 39 provider funded by the HSE or a private home care company. Regulation of these organisations that provide PA services is essential to ensure consistent care quality, safeguard vulnerable clients and maintain public trust in the home care sector. It ensures that organisations are accountable for the training, management, and supervision of their staff to ensure all clients receive safe, effective and high-quality care, regardless of the care model.



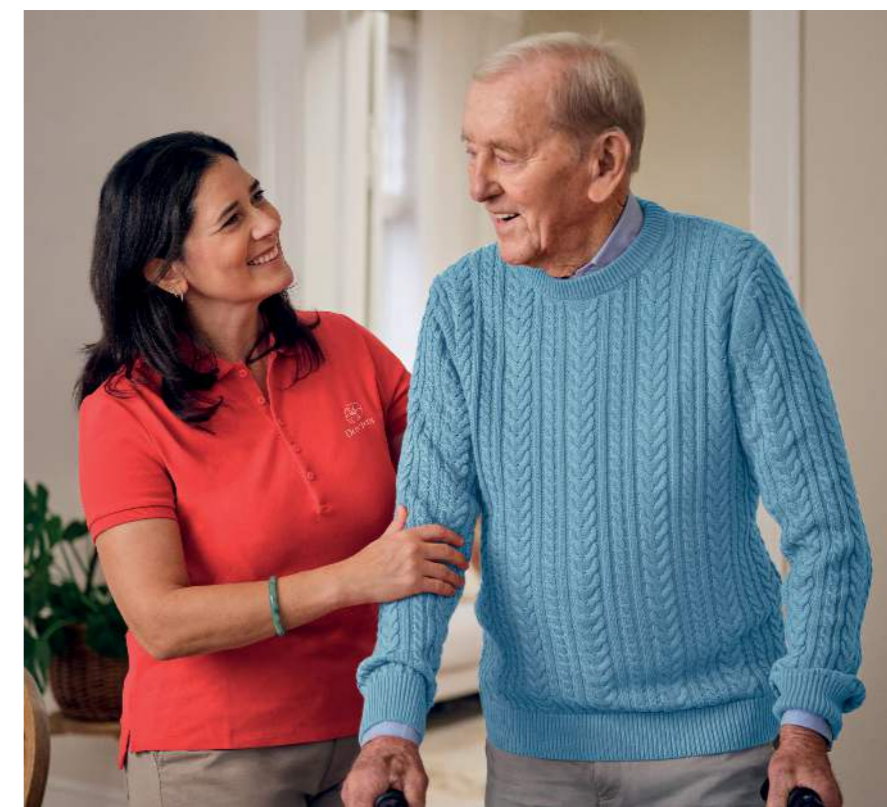
PA and home support services have more in common than in difference

The perception that PA services are mainly community based and therefore do not fit into the scope of a licencing scheme for home support providers is flawed for several reasons. The reality is that much of the care provided by PAs occurs in the home, similar to the services provided by soon to be regulated home support providers. It is important to acknowledge this overlap in both the setting and type of care provided to ensure consistent standards and to reduce risk for clients.

In Ireland, personal support to people with disabilities under the age of 65 is funded mainly by the HSE through both PA hours and home support hours. Home support hours are intended to provide home care to people impacted by their disability across their lifespan, with support focused on personal care and increasingly less focused on cooking, cleaning and light housework; whereas PA services are client directed and are mainly provided to individuals with physical and sensory disabilities under the age of 65 years (Carroll et al., 2023). PAs can be employed directly by the person with a disability, or via a third party, most often a Section 39 organisation funded by the HSE. In contrast, most home support is delivered directly by either the HSE or by private providers. For the minority of persons with a disability who have secured a personalised budget, their funding can be used for both personal assistance or home support and they have control regarding how it is spent and who provides the service (DoH, 2018).

It is widely accepted that the distinction between PAs and home care workers is unclear and blurred (Edwards et al., 2023). The HRB report (Murphy et al, 2022) described earlier noted that PA duties in Germany include personal care, household management and supporting clients to engage in social activities. Likewise in Scotland, tasks include supporting activities of family living including personal care and household management; and the Swedish PA role includes support for basic needs at home and additional needs outside of the home.

Interestingly in Sweden, it is noted that PA hours for health, care and home tasks have



increased and there is a reduction in the use of PAs for leisure and social interaction over the last five years (Murphy et al., 2022) and this may reflect the emphasis of PA supports in Swedish law: “personal assistance refers to personally designed support that is provided by a limited number of persons (personal assistants) for persons (users) who, owing to major and lasting functional impairments, need assistance with their basic needs (Act 1993:387). Basic needs are defined as; ‘personal hygiene, meals, dressing and undressing, communication with others or other help that requires extensive knowledge about the person with a functional impairment’ (Act 1993:387, §9a). If a person needs personal assistance for her/his basic needs he/she can also receive personal assistance for other personal needs if those needs are not satisfied in another way.” (Roos, 2009).

Dovida provides both private and HSE funded home support services and personal assistance services to people over and under 65 years of age. Under the current licencing plans, one part of the company’s activities will be regulated (home support), and one will not (PA services). Not regulating PA services, while regulating home support services creates an inconsistent and fragmented approach that poses significant challenges for home care companies like Dovida who offer both types of care. Furthermore, it creates a two-tier system of supports - consider these two scenarios:

Jake Age 25 Acquired Brain Injury	Michael Age 64 Acquired Brain Injury
Jake had a motorbike accident when he was 21. He is now a wheelchair user and has an acquired brain injury. He has a choice of PA who is employed through a Section 39 agency. The PA works with Jake for 20 hours a week and Jake controls what the PA supports him with. The support is personalised and varies to include having a shower daily, going to the supermarket, supporting money management, and driving him to and from work each day.	Michael was in a car crash aged 60. He is now a wheelchair user and has an acquired brain injury. He contacted Dovida to provide him with home support. Michael's caregiver is employed by Dovida and he has choice regarding who works with him. The caregiver works with Michael 20 hours a week and Michael controls what the caregiver supports him with. The support is personalised and varies to include having a shower daily, going to the supermarket, money management and driving him to and from town for lunch, to church and to attend bingo.

The reality is that both services in the scenarios above are the same. They both offer choice, control and personalisation. However, under the proposed legislation, Michael’s service will be regulated, and he will have reduced exposure to risk and harm, but Jake’s service will be unregulated, and Jake will be exposed to potential risk and harm. This is simply not acceptable.

PA and home support services are both vital to enable individuals with disabilities to live independently and participate fully in society, both at home and in the community. The current distinction made by the Health (Amendment) (Licencing of Professional Home Support Providers) Bill, which focuses on home support, overlooks the reality that many individuals require both in-home and community-based assistance from their PAs and home support workers. Indeed, research by Carroll et al. (2023) found that all HSE disability managers and non-profit section 39 providers interviewed felt that “the PA hours allocated by the HSE were all targeted at support for Activities of Daily Living (ADLs)”. This suggests that the bulk of PA services are, in reality, delivered within the home. By excluding PA services from regulation, there is a risk of creating a two-tier system where some of the most vulnerable individuals may not receive the same level of protection and oversight as those receiving regulated home care services, despite the services being sometimes identical.

The regulation debate - choice and control shall not be compromised

The debate regarding whether to regulate PA services highlights the need to balance quality and consistency, with flexibility and personalisation of care and support within the regulatory process. Arguments for regulation often emphasise the importance of standardising training and competency, ensuring safety, and providing consistent service delivery across the country. This in turn professionalises the workforce, inspires public trust and supports the principle of equity, a central theme of the UN Convention on the Rights of Persons with Disabilities.

Regulation improves governance which improves quality of care and outcomes for service users. However, arguments against regulation raise concerns about the potential loss of flexibility and personalisation, which is crucial for individualised care and support. Furthermore, increased cost and barriers to entry because of regulation could make PA services less accessible, particularly for smaller providers or those in rural areas. There is also a risk that overregulation could lead to excessive bureaucracy (Buchanan, 2014), stifling innovation and reducing the effectiveness of care and support.

However, in the absence of regulation there is increased risk of abuse of clients, abuse of staff and poor-quality outcomes for all.

Disability advocates rightly emphasise the importance of choice and control in PA services, as these principles are central to fostering independence and empowerment. Dovida advocates for choice and control for all persons in receipt of home support services but also recognises the importance of reducing risk, ensuring quality, and safeguarding that comes with regulation. Concerns by persons with a disability that choice and control will be lost if PA services are regulated are understandable but ultimately unfounded.

Regulation of PA services does not necessarily equate to a loss of autonomy or the personalisation that people value in choosing their own care and support. Instead, regulation can enhance choice and control by ensuring that all care services meet a minimum standard of safety, quality, and professionalism, thereby protecting client’s rights and wellbeing. By setting minimum standards, ensuring accountability, and safeguarding clients from abuse and exploitation, regulation supports choice and control by creating a more secure, reliable, and transparent care environment. Hearing the voice of people with disability around regulation is crucial and research suggests that regulation is favoured by the majority.

A recent Irish study involving 326 people receiving PA services (Carroll and McCoy, 2022) found that 64% agreed there is a need to increase regulation of PA provision and 79% reported that they would like to see a minimum level of qualification / training for PAs. Many called for some form of audit process for the sector.

Our call to action

The regulation of home support providers is a positive step, but it is crucial that PA services are included in the forthcoming legislation, since both home support and PA services are '*in many ways intimate*,' giving each user the possibility to '*live as others do*.' The distinction between them both is more theoretical than practical. Both types of services provide essential support to individuals under 65 in their homes and communities, often performing overlapping tasks and sharing similar goals of promoting independence and quality of life. The perceived differences are largely the result of administrative and policy distinctions, rather than any substantive difference in the care provided. A more integrated approach to regulation and oversight, recognising the similarities between home support and PA services would better serve clients by ensuring consistent quality and safety standards across all forms of home-based care and support.

While the desire for choice and control is a core principle of PA services, it is also a core principle for those in receipt of home support. It is essential to balance this with appropriate safeguards that protect against inconsistencies in service quality and potential risks. There is no doubt that the exclusion of PA services from the forthcoming regulatory framework will create disparities in the quality and oversight of care and support.

Regulation can help ensure both the protection and empowerment of people with disabilities under the age of 65, who can choose to have their PA and home support needs delivered through the HSE or through private home care companies such as Dovida.

Dovida calls on the Irish Government to amend the Health (Amendment) (Licencing of Professional Home Support Providers) Bill 2024 to include PA services without further delay.

Furthermore, we consider it timely for Government to **examine the policy of the provision of PA services to only those aged under 65**. This policy perpetuates stereotypes that diminish the autonomy and needs of older adults, denying them the right to self-directed care that would also enhance their independence and quality of life. Everyone, regardless of age, should have equal access to regulated services to support their individual needs and preferences.

Dovida is committed to delivering relationship-based care that is outcome focused and person centered, ensuring that each person's unique needs and preferences are at the heart of our service; **we urge the Government and HSE to resource and implement consumer- directed care nationally** to empower all individuals with more choice and control over their care and support at home and in the community.

To truly enable persons with disability to 'live as others do' and ensure equitable, high-quality care and support, it is essential to regulate PA services, make them accessible to all, and fully resource consumer-directed care nationwide.

References

Buchanan L. (2014) *Access to life: Personal assistant services in Ireland and independent living by people with physical and sensory disabilities*. Dublin: Disability Federation of Ireland.

Carroll, E.; McCoy, S. (2022) Personal assistance services in Ireland: A capability approach to understanding the lived experience of disabled people. *Disabilities*, 2, 694-714.

Carroll, E., Mac Domhnail, C. and McCoy, S. (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 No. 747 and Policy Paper in The Economic and Social Review*, 54(3), 193-216.

Carroll, E. and McCoy, S. (2022) Personal assistance services in Ireland: A capability approach to understanding the lived experience of disabled people. *Disabilities*, 2, 694-714.

Edwards, C., Daly, F., Kelleher, C., Loughnane, C. and O'Riordan, J. (2023) *CareVisions: Re-envisioning a care-centred society in Ireland beyond COVID-19*. Cork: Institute for Social Science in the 21st Century (ISS21), University College Cork.

DoH (2024) General Scheme of the Health (Amendment)(Licensing of Professional Home Support Providers) Bill 2024 <https://www.gov.ie/en/publication/a3ef4-general-scheme-of-the-health-amendment-licensing-of-professional-home-support-providers-bill-2024/>

HSE (2011) *Time to move on from congregated settings*. A strategy for community inclusion. Report of the working group on congregated settings.

HSE (2024) *Our National Service Plan*. <https://healthservice.hse.ie/staff/news/staff-news-listing-page/our-2024-national-service-plan/>

Larthwell, F. (2024) in [Joint Committee on Health debate Wednesday](#), 19 Jun 2024 regarding pre-legislative scrutiny of General Scheme of the Health (Amendment) (Licensing of Professional Home Support Providers) Bill 2024

Murphy, L., Farragher, L., Long, J. (2022) *The role, function, and supply of home care workers in four European countries*. Dublin: Health Research Board.

Nally, D., Moore, S.S and Gowran, R. J. (2022) *How governments manage personal assistance schemes in response to the United Nations Convention on the Rights of Persons with Disabilities: A Scoping Review, Disability & Society*, 37:10, 1728-1751, DOI: 10.1080/09687599.2021.1877114

Roos, J.M. (2009) Quality of Personal Assistance. *Doctoral dissertation*. University of Gothenburg.

UN General Assembly (2007) *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly*, A/RES/61/106, 24 January 2007, <https://www.refworld.org/legal/resolution/unga/2007/en/49751>

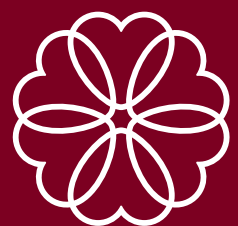


Your Life, Your Way

Block 4, Bracken Business Park,
Bracken Road, Sandyford,
Dublin 18, D18 V0Y0

Tel: 01 297 3490

dovida.ie



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