



Disability Federation of Ireland

Personal Assistance Services

Position Paper

14th October 2024

1. Introduction

A Personal Assistance, PA, service is a component in the realisation of independent living for many disabled people. Article 19 of the United Nations Convention on the Rights of People with Disabilities, UN CRPD outlines the right of disabled people to access “community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.” It gives people the opportunity to access education and employment, as well as to participate in their communities however they choose, and have an active social life.

Historically, Personal Assistance, PA services have evolved as a practice without a stated government policy position and without an acknowledged inalienable right to independent living as enshrined in the UN CRPD. In part, this has contributed to limited expansion of PA services and exacerbated inequity of access.

To inform national discussions on PA provision in Ireland and its development, this paper sets out the history of PA services; evidence from available reports on current PA service provision; international models; current and emerging issues in PA service provision; key considerations and DFI recommended next steps for PA policy development into the future.

2. What is a PA Service?

A significant feature of the PA service is the self-directed nature of the support. People with disabilities lead the service¹ and are sometimes referred to as leaders.

Disability Federation of Ireland’s research with people using PA services² outlines the distinguishing features of a PA service as follows:

- Leaders’ needs are assessed against their legitimate expectation of independent living.
- Leaders choose their PAs, with the depth of their involvement in recruitment decided by them.

¹ In the original model (still followed by Centres for Independent Living) they are referred to as ‘Leaders’.

² Disability Federation of Ireland (2014). [Access to Life: Personal Assistant Services in Ireland and Independent Living by People with Physical and Sensory Disabilities.](#)

- In selecting PAs, Leaders have access to people who respect the independent living ethos and are able and willing to work in this way.
- Leaders decide on the tasks and times of the PA service to meet their specific needs.
- The Leader's capacity to manage is respected.
- The Leader's right to privacy is respected.
- Leaders have choices about the organisation of their PA service, including the option of direct payment.
- Leaders get the preparation and support to fulfil their responsibilities.³

The assessment of need is carried out by the Health Service Executive, HSE, and a number of Leaders in DFI's 2014 research were critical of the process, particularly newer Leaders. Criticisms included that the assessment took an overly medicalised approach focused on personal care needs that did not emphasise independent living, or social activities, as well as an expectation that family members in the same household would undertake significant care duties.⁴ Leaders differed in how they wished to use the PA service, with some favouring a model of direct payments to employ their own PA. Many did not want to take on full employer responsibility, preferring an organisation to take on the administration of the service.⁵

In 2023, the HSE established a PA Review Group. One of the key outputs to date of this group has been a holding definition of PA services⁶ which states that:

"Personal assistance refers to person-directed/user-led, human delivered support available to a disabled person. A Personal Assistant, PA is chosen and directed by the disabled person to provide person to person assistance for a range of daily activities, both inside and outside the home. This remains at the discretion and direction of the individual, thus promoting choice and control to empower the disabled person to live a life of self-determination. The disabled person may devolve administrative functions for their PA to a service provider."

³ Ibid., pp. 49-50.

⁴ Ibid., pp. 34-37.

⁵ Ibid., p.45.

⁶ See pages 8-9 of this paper for more information on this Review Group.

3. Background/History

The history of PA Services in Ireland is inextricably linked to the Independent Living Movement. The Independent Living Movement was originally founded in Berkeley, California in the 1970s by a group of students with disabilities. The first Center for Independent Living was founded in 1972 "by and for people with disabilities to secure the rights, accommodations and resources needed to live and be supported in their/our communities.... Founded on the principle that people with disabilities are entitled to the same civil rights, options, and control over choices in their lives as people without disabilities." There are now over 400 independent living centres in 20 countries.⁷

In Ireland, the Independent Living philosophy was adopted as a reaction to a long-standing tradition of institutional care or family care, which were the only options open to people with disabilities. At the time, the pervasive culture around disability was one of care and passive dependency, where the individual had no control over their own lives, dominated by a charitable rather than rights-based model.

In response, in December 1992, a small group of people with physical and sensory disabilities pioneered the Personal Assistant, PA service in Ireland. They used EU and FÁS funds to finance a pilot scheme, called INCARE. The purpose of the PA service was to support independent living by adults who had previously resided in institutions or parental homes, and the person with a disability directed the PA's work. Training and peer support arrangements, including establishment of the first Centre for Independent Living, CIL, were integral to the pilot programme. Leaders recognised the value of the PA role and ensured that workers accessed training and certification.⁸ This initial PA service was essential to supporting many disabled people to move out of institutions and to live independent lives in their communities.

Reflecting on the significance of a PA service to himself and other disabled people, Martin Naughton, one of the pioneers of this first PA service, said:

"I know I wouldn't have made it to sixty-two years of age without my PAs. I mean that literally. From the day I left Baldoyle Hospital, my PAs (unofficial and official) have been with me twenty-four hours a day, turning me as I sleep, helping me in and out of bed and to the bathroom,

⁷ <https://thecil.org/about-us/our-history/>

⁸ Disability Federation of Ireland (2014), [Access to Life](#), p.16

preparing meals with me, driving me to meetings and enabling me to work and pay taxes. All human beings are dependent on others, but having a disability intensifies that dependency. Without adequate support, a disabled person like me could easily become vulnerable. In the twenty years since funded PA services were introduced, hundreds of others have left institutions as I did, or avoided going into them in the first place. Instead of living in an impersonal public space and following a daily routine set by staff, they live in their own homes and move through each day according to their private rhythms.” (Martin Naughton, *Never Know Your Place*, p.177, epilogue).

An evaluation of the pilot project conducted in 1994 found many positive benefits:

- The positive effect on individuals being able, for the first time, to take control of their own lives and exercise choice.
- Ending of dependence and ability to see independent living as a right not a privilege.
- Enhanced social participation and involvement.
- Improvement in education (27.5% of people used the PAs to attend college).
- Improvement in training options (18% of people availed of further training).
- Improvement in employment access and conditions (50% of people noted enhanced employment options as a result of the project).
- Improved subjective sense of awareness and empowerment.
- Development of knowledge and skills.⁹

The pilot funding ended in 1993, and the CIL incurred a growing deficit. Disabled people protested outside the Dáil demanding public commitment to the initiative. The Eastern Health Board took over in 1994, funding the cost of supports for each INCARE participant based on their own assessment of their needs, supplemented by advice from their CIL. As a result, IWA was contracted to run the service. The people who set-up and benefited from the pilot initiative were safeguarded in the transition, but

⁹ <https://ilmi.ie/about-ilmi/>

at that time there was no articulation of a government policy position on PA services.¹⁰

The National Disability Inclusion Strategy (Department of Justice, Equality and Law Reform, 2004) prioritised the expansion of personal assistance hours and considerable funding increases were recorded from 2006 to 2008, inclusive. However, the HSE at this time did not specifically identify the PA service, referring to 'PA/Home Support' services as a collective which, included provider managed care services.

Spending trends following 2008 were affected by the government's overriding deficit reduction priority and austerity measures. This period has brought about a confused understanding with little historic memory of what a PA Service is and is not. The reality is that for many years there was no expansion of PA hours. During this period, the only additional PA hours allocated to individuals occurred where resources were freed up due to deaths, hospital admissions and inappropriate stays in nursing homes. Basic care needs such as getting out of bed and toileting had priority over independent living and social activity supports.¹¹

Recent Budgets have begun to reverse this trend, with increases in PA funding. In 2024, an additional €2m funding was provided in the National Budget for Personal Assistance and Home Support services; estimated to provide 80,000 additional PA hours. Budget 2025 included provision for an additional 20,000 PA hours. These increases are welcome, but as they follow a decade with no increases, there is high unmet need to respond to.

See Appendix 1 for a timeline outlining the history of PA services and CILs in Ireland.

4. Current Landscape of PA Provision

The Department of Health's Disability Capacity Review to 2032 (2021) states that just under 11,000 people currently receive Home Support or Personal Assistant hours – with roughly twice as many hours provided in

¹⁰ Disability Federation of Ireland (2014), [Access to Life](#), p.19.

¹¹ Ibid., p. 21.

the form of Home Support.¹² It states that roughly 2,500 people receive a PA service, averaging around 12 hours a week.¹³

In 2023, the HSE reported the delivery of 1.69m PA hours to adults with a physical and/or sensory disability. This fell slightly short of the expected national service plan delivery of 1.77m hours.¹⁴

In 2023, the National Ability Support System, NASS¹⁵ recorded 6,533 people in receipt of 6,713 assisted living services, including home support or PA. 1,814 of these were PA services. Among those receiving assisted living services:

- **Age Profile:** 5,534 were adults and 999 were children. Almost four-in-ten (37%; 2,461) were aged 55 years or over.
- **Unmet need:** More than one-tenth (13%; 862) of assisted living services required an enhancement.
- **Primary disability:** More than half (55%; 3,501) of those who received assisted living services had a primary disability of physical or sensory, and 38% (2,438) had an intellectual disability.
- **Living arrangements:** Nearly seven-in-ten (69%; 4,048) people in receipt of assisted living services were living with family, and over one-quarter (27%; 1,569) were living alone.¹⁶

Data gaps persist on assisted living services as they do not disaggregate between those receiving home support and PA services.

4.1 PA Providers

A large proportion of PA provision is through voluntary organisations. This includes a mix of larger nationally based organisations like the Irish Wheelchair Association and Rehab Group, as well as smaller regional or local-based organisations.

To support our ongoing advocacy in this space, DFI established a PA Advisory Group to bring member organisations together who deliver PA supports. This group supports and informs our member organisation

¹² Department of Health (2021). [Disability Capacity Review to 2032- A Review of Social Care Demand and Capacity Requirements to 2032](#), p. 120

¹³ Ibid.

¹⁴ HSE (2024). [Annual Report and Financial Statements 2023](#), p.76.

¹⁵ The National Ability Support System (NASS) is a database administered by the Health Research Board that collects data on the HSE-funded disability services that people use or require in a 5-year period. [See more](#).

¹⁶ Casey, C., Fanagan, S., O'Sullivan, M., Caffrey, N., and Lynn, E. (2024). [Overview of people engaging with disability services, 2023](#). Health Research Board, p.20

representative to the HSE's National PA Working Group as well as providing peer support, networking and information sharing opportunities.

This advisory group includes the following 20 organisations from across the country, with a mix of national and local organisations:

- Acquired Brain Injury Ireland
- Central Remedial Clinic
- Cheshire Ireland
- Cork Centre for Independent Living
- Co. Roscommon Disability Support Group
- Donegal Centre for Independent Living
- Enable Ireland
- Galway Centre for Independent Living
- Irish Wheelchair Association
- Kilkenny Centre for Independent Living
- Longford Centre for Independent Living
- Leitrim Association of People with Disabilities
- North Tipperary Disability Support Service
- Offaly Centre for Independent Living
- Prader Willi Syndrome Association of Ireland
- Rehab Group
- Sligo Centre for Independent Living
- Western Care Association
- West Limerick Centre for Independent Living
- Waterford Centre for Independent Living

The Centres for Independent Living, CILs, continue to play a significant role in PA service provision. CIL PA Providers cover HSE Health Regions B, C, D, E and F (with a CIL also operating in Region A as a non-PA provider). They are all Section 39 funded organisations with Service Level Agreements.

4.2 Action Plan for Disability Services 2024-2026 and PA Review Group

The Action Plan for Disability Services 2024-2026 commits to:

- Delivering 800,000 extra PA hours to address the shortfall in services and to support people with disabilities to live a fuller, more independent life and participate in normal activities in the community, in line with Article 19 of the UN CRPD (Action 4.1).
- Conducting a policy review of PA services in light of the UN CRPD, with a working group involving key stakeholders and disabled

people's organisations, to develop formal policy and service description, develop eligibility and prioritisation criteria and consider the best form of governance and regulation.

The commitment to increasing delivery of PA services, grounded in the UN CRPD, is a progressive step, as it focuses on promoting independence and participation in normal activities in the community.

As mentioned previously, the PA Review Group was established in 2023 by the HSE, with the remit of developing a protocol for the eligibility and allocation of PA services, based on a universally agreed definition (see holding definition in 'Introduction'). Additionally, the group is to examine the legal/regulatory framework governing PA, identify gaps and areas for improvement, and make recommendations for legislative and policy changes. Its membership includes representatives of HSE, DCEDIY, DPOs, PA providers, umbrella bodies (including DFI) and disabled advocates/activists/experts.

There are several workstreams under the Group:

1. **CHO Questionnaire:** has already been issued to gain understanding of what currently exists in PA services, current allocation models, and best practices.
2. **PA National Context Paper:** to look at what regulatory and legal frameworks exist.
3. **Review of Recommendations from Department of Health Strategic Workforce Advisory Group:** Although focused on home support, these recommendations were included in the terms of reference of the PA Working Group as it has wide-ranging implications for both home support and PA in terms of pay and conditions, and recruitment.

There is an opportunity with the policy focus on PA through the Action Plan and PA Review Group to establish coherence in what has emerged as a muddled interpretation and inequitable model of PA Service delivery across Ireland. This will require continued leadership by the Department of Children, Equality, Disability, Integration and Youth, DCEDIY and the HSE, and the support of key stakeholders across government and the disability sector and movement jointly, to secure.

4.3 International Models

The European Network of Independent Living, ENIL, is a grassroots, Europe-wide and cross disability network of disabled people and their

organisations. It provides a forum for issues concerning independent living. From 2011-2013, ENIL carried out research on 22 countries, to gain information on PA services in European member states and neighbouring countries. Some of the main findings were¹⁷:

- **Legislation:** 14 of the 22 countries had some type of legislation covering PA services. The countries with national legislation were Denmark, France, Germany, Latvia, Norway, Serbia, Slovakia, Spain, Sweden and the United Kingdom. Sweden introduced the right to PA in 1994 and had the only legislation allowing for the provision of the PA service as an individual right for those eligible, with the possibility to appeal negative decisions. The British Community Care (Direct Payments) Act 1996 gave local authorities the power to make direct payments to people between 18-65, assessed as needing community care services.
- **National or regional approaches:** The level of government responsibility depends on the political topography of the given country, i.e. whether responsibility is taken up at the federal level, national level, county level or at the level of the municipality. For example, in Belgium the local authority of Flanders has over 2,000 users of a PA service while the Wallonia authority only has 250 members. In Bulgaria, PA services are only offered in Sofia, regulated by the relevant municipal act.
- **Administrators:** In most countries, the administrators of the PA service were the municipalities or a regional agency. Ten countries support the disabled person to self-direct their service and/or choose between the local municipality, cooperative or service providers.
- **Funder:** The funder of PA services is mostly the state, through municipalities or regional agencies. Just under half had PA services funded solely by local authorities.
- **Type of Disability:** The type of disabilities covered by PA services within different countries' legislation varies widely. 65% offer services to people with all types of disabilities.

¹⁷ European Network of Independent Living (2013). [Personal Assistance Services in Europe.](#)

- **Hours allocated:** 12 of 22 countries highlighted that the number of hours allocated to recipients of PA services is largely dependent on individual assessed need, with PA services in 5 of these countries also dependent on available services. Several countries have maximum caps on daily, weekly or monthly hours that can be allocated to an individual.
- **Hourly rates:** The hourly rate PAs receive varies widely due to drastically different cost of living across Europe. Within the Nordic countries, the hourly rate for PA services is much higher compared to countries within Central and Eastern Europe.
- **Assessment:** In the majority of countries, the legislation does not specify the tool to be used in the assessments of needs and it generally depends on the interpretation of the law by the local authority. Assessments are generally carried out by multidisciplinary teams led by social workers and very often include medical experts. ENIL express concern in their report that a medical approach to assessments is still widely prevalent.
- **Age eligibility:** Age eligibility varies considerably. Eight out of 22 countries excluded people with disabilities over the age of 65. However, four of these countries include people over 65 if the person has previously been assessed for PA services. Only Germany does not place any age restrictions for eligibility. A further seven countries offer a PA service to both children and adults.
- **Number of users:** Total registered users in each country varied tremendously. The UK provided for the highest number, with 100,000 users, and Sweden also had a large number of registered users (17,000). At the other end of the scale, Germany and Spain had a low number of users, highlighting the restricted nature of their PA service provision. Serbia had only 150 persons in total, Slovakia had 100 users and Iceland had 60 persons taking part in a trial project.

Examining the operation of different countries' PA models is valuable in determining a way forward for Irish policy. DCEDIY have committed to commissioning an evidence review of PA in the international context. The evidence from the review will inform ongoing discussion on questions such as:

- Is there agreement on what a model of PA best practice looks like?
- What is considered to be a sufficient level of service?
- What should eligibility criteria look like?
- Do we need a standardised assessment tool?

A starting place for international comparisons is to identify different or similar definitions of PA services. There are a number of definitions of PA services used internationally. Some of these are outlined below:

1. **ENIL** (European Network on Independent Living) defines Personal Assistance as a tool which allows for independent living. Personal assistance is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance should be provided based on an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model which is most suitable for our needs. Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance. **(ENIL's Proposal for the EC Guidance on Independent Living and Being Included in the Community)**.
2. Personal assistance means necessary assistance for a person with severe disability at home and outside of the home. A personal assistant helps the person with a disability in the tasks that the person would do without help if there were no disability. The assistance can take various forms, depending on the person assisted. It can be related to eating, washing, toilet visits, dressing, household chores, running errands, studying, working or participating in public activities. **(Finnish Institute for Health and Welfare)**.
3. Independent living means having the same choices and control in everyday lives that non-disabled people take for granted. Personal Assistants (PAs) are people who support their disabled employer to live an independent life. The main difference between a personal assistant and a paid carer/ support worker is that the PA is accountable to their

disabled employer, who, in turn is responsible for the welfare and safety of the PA, as well as their conditions of employment. (**Scottish government**).

4. Personal assistance is a mechanism to support users for full participation in society, to carry out activities corresponding to the personal, domestic or social needs and to overcome the obstacles to the functional limitations. The mechanism is based on state-guaranteed financial support, individual needs and the personal choice of the personal assistance user. (**Republic of Bulgaria**).
5. The aim of the programme is to introduce the personal assistant service as a form of public support for persons with disabilities. Due to the programme, persons with disabilities will be able to receive assistance of a personal assistant, e.g. in performing everyday activities or undertaking social activity. The programme also aims to counteract discrimination and social exclusion of persons with disabilities. (**Ministry of Family, Labour and Social Policy; Republic of Poland**).

5. Current and Emerging Issues

There are a series of identified issues in relation to current PA service provision including:

- lack of available data;
- identifying levels of unmet need;
- supply issues including retention and recruitment of staff;
- dilution of service;
- developments in home support;
- access for people aged over 65 years;
- standardisation and quality.

5.1 Unmet Need for PA Hours

As noted above, a major challenge in relation to PA provision is the lack of appropriate data on the level of need. The Disability Capacity Review to 2032 stated:

“While the organisations working in the area of physical and sensory disability report considerable shortfalls in the level of provision relative to need, there are little or no usable data on the scale involved. This is because it

has not been the practice by service providers or the HSE to document unmet need for these services.”¹⁸

The review also states that “unmet need has not been systematically recorded” and that “the National Ability Support System will begin to collect more comprehensive information on unmet need”.¹⁹ This data needs to be strengthened to ensure that full data is captured on NASS, including data from smaller, locally based providers, who have more limited resources to engage with the system.

The data that is available, suggests significant unmet need for PA services; - both among those who do not have any PA service and among those who **do** have a PA service, but receive insufficient hours to meet their needs.

The Disability Capacity Review (2021) found that 2,500 people receive a PA service averaging 12 hours a week.²⁰ The ESRI’s Personal Assistance Services in Ireland: A Capability Approach to Understanding the Lived Experience of Disabled People (2022) findings were broadly in line with this average, while also finding a wide variation in weekly hours among survey respondents. ESRI’s study (N=326) found that survey respondents received a median of 10 hours per week. The number of hours received varied widely among the sample:

- 31% of respondents were receiving less than 5 hours per week.
- 23% of respondents were receiving between 5.5 to 10 hours per week.
- 24% of respondents were receiving between 10.5 to 25 hours per week.
- 22% of respondents were receiving more than 25 hours per week.²¹

Information submitted by the HSE to the Committee on Public Petitions in 2018 outlines 1.51 million PA service hours were delivered to 2,470 people in 2017. However, these figures showed that 84.44% received less than three hours per day on average, with 44.41% receiving on average 42 minutes per day.²²

¹⁸ Department of Health (2021), [Disability Capacity Review to 2032](#), p.121

¹⁹ Ibid. pp.121-122

²⁰ Ibid.

²¹ Carroll, E., and McCoy, S. (2022). [Personal assistance services in Ireland: A capability approach to understanding the lived experience of disabled people](#), Disabilities, p.700

²² See [ILMI Personal Assistant Services Campaign](#)

Delving deeper into available data, the descriptive statistics of the ESRI's research outlines significantly higher PA allocations among those with higher levels of education, living in urban locations, and with lower levels of "natural support" i.e. unpaid assistance from family and friends.

Regression models show a variation in PA intensity across both geographic and social support indicators. People living in a city, and those living in Dublin receive significantly more hours. Those accessing support prior to 2010 also typically receive greater levels of supports. As the researchers suggest, this is perhaps unsurprising given the funding cuts in the context of the period of austerity.

Overall, more hours of assistance received from family is linked to a lower package of hours, while difficulty getting help from a neighbour is linked to a higher package of hours. More hours were widely called for.²³

NASS also records a requirement for new assisted living services i.e. new places required by people not in receipt of assisted living services but who need it now or will need it within the next five years. Service providers identified 663 people in 2023 as requiring 694 assisted living services. 199 of the services required were identified as PA services. Of those requiring assisted living services:

- 65% (433) were aged 35 years or over, 29% (191) were aged 18-34 years and 6% (29) were aged under 18 years.
- 58% (384) had an intellectual disability and 32% (210) had a physical or sensory disability:
 - Of those with an intellectual disability, 290 of the assisted living services required were for home support, and 94 were for a PA.
 - Of those with a physical or sensory disability, 122 of the assisted living services required were for home support, and 95 were for a PA²⁴

The data captured on unmet need in NASS is very likely to be an underestimation of the full level of need, as it only captures those who are already engaged in some way with disability services.

²³ Carroll, E. and McCoy, S. (2022), Personal Assistance Services in Ireland, p.701

²⁴ Casey, C., et al. (2024), Overview of people engaging in disability services, 2023, p.27

5.2 Recruitment and Retention of Personal Assistants

Recruitment and retention of PAs is a major issue that is impacting on support/service delivery. To maintain and expand access to a Personal Assistant service and respond to unmet need, staff need to be in place to provide any additional hours that are funded. The issues regarding the PA workforce is linked to the recruitment and retention issues that are there for the health sector as a whole. As the majority of PA services are provided by Section 39 funded organisations, the lack of pay parity with HSE and Section 38 funded organisation is also having a significant impact.

The following are additional concerns and issues (and possible solutions) raised through DFI's PA Advisory Group which comprises organisations working in the provision of PA supports:

- There is no standard, agreed cost for the delivery of PA services. This means that two PA providing organisations may be receiving differently hourly rates of pay from the HSE to deliver the same service. This may have evolved in different regions without coherency with other areas, or at different times in the same region. There is a need to ensure equitable pay rates both across regions and within the same region. It is worth considering a recommendation of the Report of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services (2018) that the State decide on a list of essential services to be provided to the population and commission these based on a nationally fixed price.
- The agreed hourly pay rate received for PA provision is lower than that for home care workers in Older Persons Services. Older Person's home carer rates were also recently raised. Two regions have raised the PA pay rate to match this, while others have not. This creates further challenges in relation to the recruitment and retention of PAs. DCEDIY's allocation in Budget 2025 included funding to progressively align the PA and disability home support rate with Older Persons' Services to sustain workforce capacity.
- Competition with private providers is a major issue in relation to the delivery of PA Services. The HSE commissions many private agencies to deliver PA hours at a higher cost than offered to the voluntary sector. This means that voluntary providers, in providing the service at a lower cost, are unable to compete with private

providers in relation to staff pay. It also means that an increasing level of provision is moving into the private sector, at significant cost to the state.

- Challenges with current social welfare structures. For example, many PAs work part-time while receiving a social welfare payment. Therefore, reforms that enable people to work more hours, and more flexibly, while retaining access to social welfare payments, would assist with staffing challenges. National recruitment campaigns should also reflect this staff profile. Recommendation 8 of the Department of Health's Strategic Workforce Advisory Group report states that a review should be undertaken of eligibility criteria for State benefits with a view to ensuring that they do not disincentivise part-time employment. In particular, the stipulation that recipients of Jobseeker's Allowance can only claim benefits for days they do not undertake any paid work should be re-examined to allow a move from days worked to hours worked. This recommendation would have a positive impact in relation to PA recruitment and staff shortages. Changing thresholds to allow experienced and available staff to work more hours per week is an urgent priority.
- Being excluded from international recruitment drives. PAs should be included in European Employment Services, EURES, and removed from the ineligible occupations list, as has taken place with Home Care/Home Support workers. However, it is difficult for voluntary organisations, particularly smaller locally based organisations, to engage in international level recruitment campaigns such as EURES, e.g. supporting relocation grants and formal training is challenging for small organisations with limited resources. Engaging with organisations, through umbrella representation, would support engagement with EU level recruitment campaigns to ensure the inclusion of the voluntary disability sector.

5.3 Dilution of PA Services

The ESRI's aforementioned report, *Personal Assistance Services in Ireland: A Capability Approach to Understanding the Lived Experience of Disabled People* (2022) highlighted:

- 38% of respondents said that PA assistance was meeting their needs.

- 71% used the PA services for support for personal care.
- 79% used PA services for activities of daily living.
- The median number of PA hours received is 10 per week²⁵

These results would suggest a certain level of dilution of the initial intention behind a PA service, with 71% using their PA service for personal care, which would traditionally fall under the bracket of a home help/home support service, rather than PA. Furthermore, the median number of hours per week (10), which equates to less than two hours per day would practically inhibit the level of support for independent living (e.g. engaging in employment, socialising, accessing education) that could be provided.

DFI's aforementioned Access to Life (2014) report found that during the austerity period, funding for PA services decreased, with prioritisation of personal care provision over social support increasing. This led to a dilution of the meaning and understanding of a PA service.

The Disability Capacity Review to 2032 (2021) stated that "the budget for PA services has remained unchanged since 2008, so the HSE has been managing a fixed number of support hours each year. As a result, as reported to the Dáil, the HSE may from time to time reduce an individual's support hours in order to address priority needs of other people with disabilities within that community." The review also stated that "unmet need has not been systematically recorded," with the National Physical and Sensory Disability Database and National Intellectual Disability Database (now merged into the NASS database) only capturing "negligible levels of unmet need." It also highlighted that "pent-up demand for residential placements and respite from people on the emergency list has resulted in the increased usage of in-home support hours as a holding strategy to somewhat ameliorate the high risks in the home. This consequently limits the availability of hours to other people with disabilities requiring home care or Personal Assistance."²⁶

While increases in the PA hours have been included in successive budgets since 2020, it must be acknowledged that this came from a low starting base, after a decade with no increased investment, with demographic change and unmet need increasing.

²⁵ Carroll, E. and McCoy, S. (2022), Personal Assistance Services in Ireland, pp.700-703.

²⁶ Department of Health (2021), Disability Capacity Review to 2032, p.121

“I wish I could say for certain that institutionalisation was a thing of the past, and that the right to PA services could be taken for granted, but budgets are being cut regularly, or tweaked off radar, and there are huge regional inequalities. An increasing number of young disabled people are not being allocated enough PA hours to enjoy the kind of freedom I have had. This is not the spirit of Independent Living that my generation fought so hard for. Before I hang up my cap, I hope to see the next generation of Irish activists come together to protect the PA service and to envision what a better future might look like for disabled people in Ireland.”

(Martin Naughton, *Never Know Your Place*, p.180, epilogue)

5.4 Impact of Lack of Hours on Independent Living

A lack of a PA service, or insufficient hours, has a significant impact on disabled people’s ability to live independently. The delivery of accessible housing, along with a PA package can be a building block to independent living. This requires PA and housing supports to be planned and delivered in tandem, however frequently even when people are offered an accessible home, they are not able to access a HSE PA support package that meets their needs.

A PA service needs to follow the person throughout their life course. However, often when people leave education, they lose access to their PA service. This inhibits people’s ability to access meaningful work after completing education, and can also lead to people choosing to stay in education longer simply to retain access to the PA support that they need to be independent.

A lack of PA hours also inhibits meaningful participation by disabled people, for example disabled people may not be able to attend consultation meetings and events on issues that affect them due to not having access to a PA.

5.5 Developments in Home Support Services

The Department of Health is progressing a regulatory framework for home support providers across both older persons’ and adult disability services. The regulations will establish a licensing system for providers of home support services, and confer on HIQA and the Chief Inspector the authority to grant, amend and revoke a licence if home support providers

fail to meet minimum requirements. Under the draft regulations, it is intended that PA services will be excluded to allow for the separate regulation of PA at a future date.

Although PA services are excluded from the draft regulations, many providers operate both home support and PA services. Therefore, it is likely that the regulations will have an impact on PA providers. Providing home support and PA staff through different suppliers would not be a viable solution as it would disrupt continuity of service provision, with many different staff visiting weekly.

It was decided through public consultation that PA services would remain separate from the licensing and regulation of home support services due to the distinctiveness of the services; and this is welcomed. It is expected that PA services will likewise be subject to public consultation, regulation and licensing and again a welcome development by those providing and using PA supports. There is a need to ensure that when licensing and regulation of PA services occurs, it takes account of the person-centred nature of the services and the emphasis on promoting independence. There is learning to be taken from previous expansions of regulation to disability services, e.g. residential.

5.6 Developments in Older Persons' Services - Procurement for Adult Disability Services

It is useful to examine developments in the delivery of home supports in Older Persons' Services, while recognising that PA is a different service. Appendix 2 provides an overview from the Irish Wheelchair Association of the difference between Older Persons' Home Support Services, and a PA service, from their perspective.

A Strategic Workforce Advisory Group on Home Carers and Nursing Home Health Care Assistants (mentioned above) has provided a series of recommendations that improve pay, conditions and development opportunities for staff in the Older Person's sector. InterRAI has been selected as the single assessment tool for Older Person's services in the community, and a recruitment process will take place for a National Home Support Office for Older People, with manager/coordinator posts in each CHO. Development of an Older Persons' home support IT system is also underway.

By comparison, there is no overarching policy for the provision of PA to people with disabilities, and a single assessment tool has not yet been

agreed for disability services. Additionally, there are no staff dedicated solely to PA at a national level, with decisions around service provision being taken at Head of Service of Disability Manager level, which increases the level of regional variation in PA service delivery.

There have been a number of changes to tendering and commissioning of PA services which have been brought about due to the Strategic Workforce Advisory Group on Older Persons' Services. As this was not developed with disability services or PA in mind, there is a need to ensure that any approach to procurement of PA services does not duplicate this approach. For example, the tendering for Older Persons' Services requires capacity to deliver services regionally. However, the scale of Older Persons' Services is not comparable to PA. In PA services, there are a number of smaller, niche, locally based providers central to the service provision landscape who would not be able to apply. The model of service provision in Older Persons' Services and PA services are very different, with Older Persons' Services focused on medical care, and PA services focused on independent living supports based on the social model of disability. There is a risk that a one-size-fits all procurement process would dilute the principles of PA services.

A further concern relating to procurement is that the HSE can grant tenders based on economic considerations, rather than user-needs. This means that services with a user-led, independent living ethos lose out in competitive tendering processes, to the detriment of the individuals receiving services.

5.7 Inequity of Services for those Aged Over 65 Years

Disabled people in Ireland over the age of 65 are not eligible to access a PA service in Ireland. At that age they can be transferred into Older Persons' Services which provides home based help/care. According to research by the ESRI, in some cases a PA service is maintained for those already receiving a service although this appears to be inconsistent. However, there is no allocation of PA services for those already over the age of 65, even if this would better suit their needs.²⁷ Home care through Older Persons' Services is entirely different to a PA service. It is not Leader/user-led, it does not accommodate any service beyond that of

²⁷ Carroll, E., Mac Domhnaill, 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"](#), Economic and social Review, Vol. 54, No. 3 Autumn 2023, pp. 193-216.

personal care, and it does not facilitate support outside of the home. While Older Persons' Services may be appropriate depending on people's profile of needs, the needs of many disabled adults are best maintained through their own self-directed PA service.

5.8 Quality and Standards

Due to a lack of historic policy focus on PA, many of the existing frameworks in relation to quality and standards in disability services are not directly relevant to PA services. This contrasts starkly to provision of services delivered in line with the Transforming Lives policy (2012).

PA services lack the embedded structures, frameworks and policies that have developed in HSE residential, day and children's services, which have received greater policy focus over the past decades. In contrast to other areas of service provision, there is also a lack of dedicated, national staff in the HSE with a focus on PA to drive policy and oversee quality and standards for PA. Alongside the work of the HSE's PA Review Group, quality and standards frameworks and infrastructure that are directly applicable to PA services must be developed. These should be designed in collaboration with PA service providers, in line with the Dialogue Forum Partnership Principles, and in collaboration with PA users/Leaders.

5.9 Personalised Budgeting

PA and personalised budgeting are intrinsically linked. They both speak to agency and autonomy, and involve directing your own service. A personalised budget is an amount of money that is given to a person by public authorities, such as a Local Authority or a public health service. This budget is for the person to decide how to use it to meet his/her support needs and arrange the support he/she needs.

Personalised budgets promote greater choice and control for individuals. While they can be used for a broad range of services, often they include directly hiring a PA.

We don't have a tradition of personalised budgeting in Ireland and there has been no major investment or reform in this regard. The pilot project on personalised budgeting in Ireland involved a model that was not workable due to the level of administrative burden that was involved for individuals, as they were required to set up and run their own company. There is a need to develop a workable model in Ireland based on international best practice.

There is much international evidence and research on personalised budgets, including an EU project DFI contributed to. 'UNIC' - towards User-centred fuNdIng models for long term Care' examined different models and good practice internationally in relation to personalised budgeting. [Read their report here.](#)

PA providers and users/leaders can make a valuable contribution to the development of personalised budgeting, due to their historic experience of managing administration, compliance, finance, HR, etc. This has involved meeting a wide range of differing needs, including augmentative and alternative communication, aids and appliances and other requirements in support of full accessibility of the PA service, such as access to staff trained in Sign Language interpretation.

An individual's capacity to fully avail of a genuine, user-led PA service (and similarly, personalised budgeting) may often require capacity building, support and ongoing service intervention.

6. Key Considerations and Next Steps

The paper above has set out the context around the development of PAs in Ireland. The original ethos of PA services cannot be lost and further development of policy and expanding access to PA services is required to realise the UN CRPD and the rights of disabled people to live lives equal to others. This requires:

- Recognising the foundational purpose of PA services as self-directed care, promoting choice and control, and the distinctiveness of PA in comparison with home care. The ethos and spirit of the PA service needs to be preserved in future policy and implementation.
- Funding increases to redress the balance following minimal and inadequate investment into PA as a result of austerity measures. As noted in the paper, funding remained unchanged from 2008 to 2019. This resulted in a degradation of the founding purpose of PA services to promote independent living. There is a need for significant funding to redress this legacy of underfunding, as well as a renewed policy focus with a clear definition of PA services, developed through the PA Review Group.
- Pay rates must be aligned and standardised across the country. Without this, equitable provision of services regardless of location will not be possible.

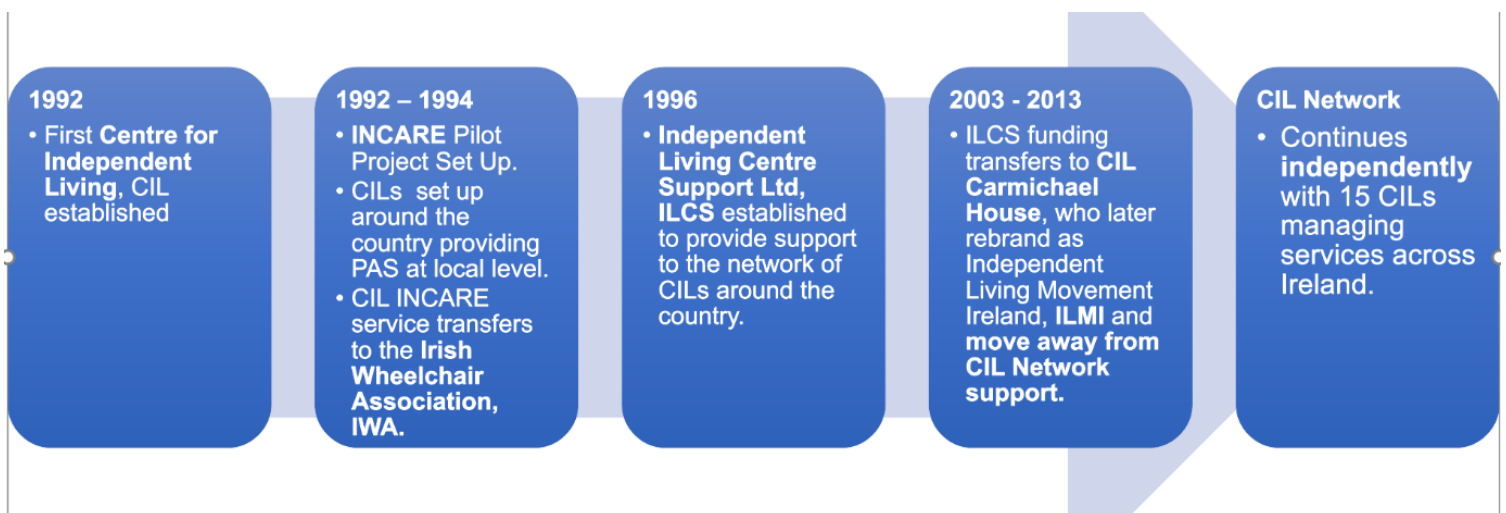
- There is a need to ensure decent pay and conditions for PAs, with a standard pay rate regardless of location or service provider. Pay parity for Section 39 funded organisations is a key priority, to support recruitment and retention. Being a PA can be a worthwhile career option however, there is a need to re-examine terms and conditions, pay and training in this context.
- Recognition of the current landscape of service provision, which includes a large quantum of hours provided by smaller, locally based organisations including the Centres for Independent Living. This must be factored into policy development and there is a need for strategic engagement with these organisations, including through the newly formed National Alliance of CILs and DFI.
- Improving data gathering and integrated data collation/collection systems to support accurate identification of unmet need. Improving systems to track unmet needs will help make better policy decisions.
- Recently, DCEDIY has turned attention to PA services, and this is welcomed as policy attention is being placed on this support. HSE staff dedicated to PA at national level are also required – driving development and ensuring a clear policy line to direct equity of services regardless of region and service provider. Dedicated national staff would provide leadership and drive consistency of service.
- Look to models and examples of PA in other jurisdictions and develop a workable model for Ireland.
- Leader/PA combined training could be an important element in maintaining the foundations that informed the establishment of the model originally.
- The need to move away from siloed service provision, recognising PA as fundamental to supporting deinstitutionalisation, integrating into housing to facilitate independent living, enabling access to education and employment, etc.
- There is significant regional variation and inequity in the availability of PA services. To address these variations in funding, needs-assessment, principles of provision, and working conditions across different regions (and even within regions) need to be addressed.

Ensuring that national policy in relation to PA is delivered equitably across the Health Regions requires specific focus. The Action Plan for Disability Services plans for the delivery of an additional 800,000 PA hours by 2026 and there is a need to ensure that increases in service hours are delivered equitably across regions and do not exacerbate inequalities.

- It is the position of the Disability Federation of Ireland, DFI, that provision of a Personal Assistance, PA Service is the right of disabled people who require this service, as affirmed in the United Nations Convention on the Rights of People with Disabilities, UN CRPD. The right to this service is a priority to be acknowledged and accepted by all state bodies.

7. Appendices

7.1 Appendix 1- Timeline of PA Service and CIL Development in Ireland



Source: CIL Network Presentation to HSE, 15 August 2023

7.2 Appendix 2- Difference between a Personal Assistant Service and Home Support Service for older people- IWA perspective

Home Support Service for Older People	Personal Assistant Services
<p>Definition:</p> <p>The HSE Home Support Service (formerly called the Home Help Service or Home Care Package Scheme) aims to support older people to remain in their own homes for as long as possible and to support informal carers.</p>	<p>Holding definition:</p> <p>Personal assistance refers to person-directed / user-led, human delivered support available to a disabled person. A Personal Assistant (PA) is chosen and directed by the disabled person to provide person to person assistance for a range of daily activities, both inside and outside the home. This remains at the discretion and direction of the individual, thus promoting choice and control to empower the disabled person to live a life of self-determination. The disabled person may devolve administrative functions for their PA to a service provider.</p>
<p>Clinical Model, focusing on care and tasks.</p>	<p>Person Centred Approach, offering as much choice and control as an individual wishes.</p>
<p>Service model designed by funder, sometimes in consultation with family, often provided as additional support to family members.</p>	<p>Service model designed with the individual to prevent family members from potentially only having a caregiver relationship with the individual. Also, service is designed with input from the individual on what they want from their service and how they want it delivered.</p>
<p>To support individuals to remain living safely in their homes and to prolong the requirement for them to be transferred to nursing homes.</p>	<p>Support individuals to live independently and to maximise their opportunities to participate in society like their peers.</p>
<p>No input into what care assistant delivers your service.</p>	<p>Choice in relation to PA selection where possible and matching.</p>
<p>Services provided through minimum hours and is normally for a short period of time.</p>	<p>Hours can be up to 24/7, lifelong services.</p>
<p>Delivered in home</p>	<p>Delivered in Home and Community Settings</p>
<p>Service provides:</p> <ul style="list-style-type: none"> • getting in and out of bed • dressing and undressing • personal care such as showering and shaving 	<p>Service providers:</p> <ul style="list-style-type: none"> • support with everyday tasks • personal care etc • shopping • education • employment • social activities / family engagements