



Not in the Driving Seat

Reliance on family for supports and the impact it has on the lives of disabled people

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Investment in supports that liberate disabled people will also liberate family members to move from roles where they provide support for their partners, children, or siblings, and can focus solely on their family relationships.

Des Kenny, ILMI Chairperson



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Inside



Executive summary

04



Introduction

07

Review of literature

08

Methodology

09

Views of Disabled People on the impact of family on caregiving

11

Summary

17

Recommendations

18

References

19



Click on the title or page number to go directly to page

Foreword

Independent Living is the right of all persons regardless of age or impairment to live in the community; the right to have the same range of choices everybody else in housing, transportation, education and employment; the right to participate in the social, economic and political life of own communities; the right to have a family; the right to realise one's own potential, and the right to have the freedom to live a life of one's own choosing in an inclusive society.

The Personal Assistance Service (PAS) is a service that allows us to live independently. This service enables us to do all the tasks that we cannot do for ourselves. It provides us with the freedom and flexibility we need to live our lives as we choose. A Personal Assistant (PA) is hired to assist us with a range of day-to-day tasks that we cannot physically do for ourselves. With a PA we are in control and direct the PA to carry out tasks both inside and outside of the home, including personal care, domestic duties, assisting in day-to-day tasks such as shopping, support in the workplace or socialising. A PA does not "look after" or "care for" us. We delegate these tasks to our personal Assistant and in doing so direct control of our lives.

A distinct benefit of the PA service is that it reduces our dependence on our family and friends. The confidential relationship that develops between our PAs and us allows us to maintain a private life with dignity. A Personal Assistant is often the difference between merely existing as distinct to meaningful living for many of us.

Currently, in Ireland, there is no legal right to a PA and the formal provision of the service for disabled people. There is no national system to standardise how PAs are provided, funded, assessed and supported. These are all central aims of the ILMi PAS NOW campaign to establish a national system for our PAs to ensure that we as disabled people have the supports we need.

Independent living is ultimately about living our lives with choice and control. It is about deciding how we want to live every hour and how to manage our lives on an ongoing basis into personal fulfilment, to participate when we choose and to own making decisions on events in our lives. It can be summarised as the fundamental expression of ourselves as human beings and taking our place in society as equals.

This fundamental right is today at the core of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which sets out our right to participate as equals in all aspects of life in a society that embeds inclusion in all that is designed and delivered.

Sadly, in the absence of a structured approach to obtaining a personal assistant and a rational service to support it, many disabled people do not know about a PA and, as a consequence, are denied the right to live lives of independence and inclusion in the fashion non-disabled people take for granted. Many access day and residential services that segregate us and deny us the choices to participate in mainstream education, employment and social activities are the product of this absence.

Many disabled people (too, too many) get no PA hours or struggle with meagre hours which do not allow one to live independently. Many disabled people are forced to rely on family members for supports to do the things that can't be done by ourselves. There is ample research on the stressful impact on disabled people and family members who provide support to disabled people. Typically, we hear of the "burden of care" we have become but never do we hear of the voices of disabled family members who, due to the absence of PA hours, are forced to rely on members of the family for support. We never hear of the impact on their lives and their relationships with family members, the compromises they have to make and how they are denied opportunities to do what they want, the unprinted burden of the "cared for one".

This research, which was carried out in 2021, aims to give voice to some of those concerns and in doing so, shows that real investment into a national PA service can liberate disabled people and transform family dynamics for the better for many families. Typically, the narrative for far too long has been of family carers and Disabled Persons Organisations (DPOs) in opposition to one another in terms of allocation of resources.

ILMI feels this research should challenge and change that narrative. Investment in supports that liberate disabled people will also liberate family members to move from roles where they provide support for their partners, children, or siblings, and can focus solely on their family relationships.

This research shows once again the value of investing in a PA service to give disabled people choice and control. Our hope in ILMI is that organisations led by family members and family carers will find much in this research to illuminate their work and campaigns. Our contention is that if the Irish Government is serious in fully realising the UNCRPD, it needs to invest in systems that meet the needs of disabled people. By designing and investing in a PAS system that gives disabled people the choice and control they want in their lives, it will at the same time meet the needs of families and carers in Ireland.

I would like to thank Marie Lynch who carried out this research on behalf of ILMI. I would also like to thank the disabled people who gave up their time to share their rich life experiences in order that we might learn about how the lack of supports impacts their lives and the lives of their family members.

Ultimately family members and disabled people all want the same thing. Until now we have been separated in creating a unified voice demanding the same thing. By uniting to call for PAS NOW, disabled people can be liberated to participate in society as equals, and family members can continue to be our strongest allies in achieving that right.



Des Kenny, ILMI Chairperson.
May 2023

Introduction

a) Context

This report seeks to examine the impact that forced reliance on support from family members has / has had on the quality of life, and self-determination of disabled people.

Nationally and internationally there exists an abundance of research which explores the impact on family members who provide supports for disabled family members. However, there is a significant absence of research documenting the impact that reliance on family members has on disabled people.

b) Purpose

The purpose of this research is to enable disabled people to share how the lack of independent living choices, resulting in a reliance on family members, has impacted on their lives.

ILMI intends to use the research findings to initiate a more holistic exploration of the impact of family caring and to highlight the importance of access to independent living for disabled people.

c) Objectives

The following objectives were set for the research.

1. Review and analyse national literature in relation to family members providing care and supports for disabled family members and specific references to the impact on disabled people's lives.
2. To create spaces for disabled people who rely on family members for support and assistance to have their voices heard.
3. To document the impact on disabled people themselves of having to rely on family members for assistance.
4. To ensure disabled people's voices are central to any discussion about care or the impact of caring on family dynamics.

d) Scope

Whilst the research focuses on impact on disabled people themselves of having to rely on family members for assistance, it also shows where disabled people have the supports that they need have greater independence. For the purpose of this report family members includes parents, siblings, partners and children.

e) Oversight

A project steering group, which was representative of the board and staff of ILMI, was established to link with the researcher (Marie Lynch) who was commissioned to carry out this report.

Review of literature

During the initial discussion with the project steering group, it was indicated that there was a dearth of literature on this topic. This view was confirmed following a desktop review of literature, EBSCO online search and discussions with research staff in CDLP NUIG Galway.

However, a number of articles and publications which examined the need and models of PA service, indirectly addressed how this service would impact family relationships. The 2017 ENIL publication acknowledged that exclusive reliance on family can restrict autonomy of disabled people and does not allow for choice and control over assistance (ENIL 2017). The DFI publication (DFI 2014) stated how leaders feel equal because they no longer impose on family, and it enables quality time with family.

Having a PA means you do not have to rely on family for every day mundane tasks, and the time you spend with quality can be quality time.

DFI 2014

A Swedish study that examined paid personal assistance from family members noted that this relationship could both be a barrier and promote disabled people's control over their own lives (Duner and Olin 2017).

The following themes were extracted from the discussion with the Steering group, Centre for Disability Law and Policy in the University of Galway and the available literature:

1. Managing and exploring boundaries
2. Addressing the compromise
3. Balancing privacy with flexibility
4. Maintaining healthy relationships

Methodology

This section outlines the two approaches which were utilised to gather information (focus group and individual interviews), as well as the selection of the participants and their profile. The final section addresses the limitations of this work.

a) Participants

Participant selection- focus group and interviews

A communication note was circulated to ILMI members notifying them about this research and seeking expressions of interest for participation. This was followed up by ILMI staff members who contacted individuals who had indicated their interest in participating.

A total of 13 people participated in the research.

Participant profile - focus group

Six people participated in the focus group which was held using Zoom and lasted an hour. Five had access to PA hours, and just one had enough hours to facilitate them living independently from their family members.

Participant profile - interviews

Eight interviews were conducted. One of those interviewed had previously participated in the Focus group. All of the participants had access to a PA service; only one did not rely on family members for any support. Two participants still lived in or adjacent to the family home.

b) Focus group

The themes were circulated ahead of time to facilitate participation. Permissions were sought to record the meeting to enable transcribing, and consent and confidentiality protocols were followed in accordance with ILMI policies and procedures. Two ILMI staff members joined the meeting as observers.

The focus group was transcribed and themes were extracted and a report was prepared and shared with the ILMI staff with suggestions for next steps. These themes were used to inform topics for the interviews.

c) Interviews

All the interviews were held using Zoom, and the researcher contacted the participants directly to arrange a suitable time. The meetings were recorded with permissions, and the confidentiality protocols were reiterated at the start of each interview. In addition, participants were reminded that they could cease their participation at any time. The interview themes were circulated to the participant ahead of the meeting.

Each of the interviews were transcribed, and themes and issues arising from each interview were summarised and subsequently combined, using open coding.

c) Interviews

As there was an open invitation to participate in this research, the people who engaged in the research were those that felt comfortable to speak on this topic.

Although the participants represent both those who are still quite reliant on family members and those who are independent of family support, the profiles of each participant were deliberately not captured, and specific comparisons are not possible.

The sensitive nature of the topic generated some emotional responses for the participants, and the use of virtual communication may have impeded the ability to fully address this personal topic.

While the research question is specifically about reliance on family members, the discussion and conversation that ensued with participants was invariably linked to the impact on introducing PA service, as this gave a sense of perspective and comparison and this is reflected in the discussion. However, in some cases, the lack of PA service and difficulties with the structural aspects of PA service dominated the discussion, and other themes arose in relation to value of role models. To keep the report concise, these have not been captured in this report, but have been made available to ILMI for future reference.



Views of Disabled People on the impact of family on caregiving

The key objective of the research was to document the impact on disabled people themselves of having to rely on family members for supports. The views that were expressed by 13 disabled people who participated in this research have been transcribed, and themes and issues arising from each interview were summarized and combined, using open coding. The following four themes subsequently emerged and are explored in detail in this section.

Themes

1. Spontaneity
2. Choices
3. Compromise
4. Privacy

1. Spontaneity

Personal autonomy allows for spontaneity, not having to plan too much and getting a sense of flow, and for some taking risks. The lived experience of those who participated in this research identified the value they put on having fun with their family and being able to make their own decisions, without relying on family members. Others indicated the effort it took to plan events and how inhibited they were when relying only on family members or friends for support.

Not relying on family members for support has enabled people to enjoy family company and play an equal part of family life, as well as being able to have a normal life.

The more assistance you have the better relationship you have with your family. You can go out and have fun with them. Or just have the craic... hang out and chill. (8)

I had two weeks with a PA 24 hours per day for a camp – it took six months to plan. I loved every minute of it. It was amazing. I remember going home it was such a contrast. I cried for four hours because I had the taste of freedom. (1)

I love the freedom of getting a task done without having to wait 'til a family member is ready to help. It's much easier and empowering and less stressful that you just get something done. Stronger when have the independence from family. (6)

It was great – I could go for a walk when I wanted, I could have my lunch at a time I choose. I could go to the bathroom when I wanted... rather than waiting for the right moment. I could go shopping when and where I wanted. (3)

It's nice to be able to give something back to family - I can do this with my PA. (4)

The PA helped me build friendships when I was in college. (13)

Whilst the PA has helped my autonomy, my family like to remain involved, which can be a bit restrictive for me. (11)

For those without a comprehensive PA service, the need to continually plan, or not be able to come and go takes its toll and inhibits how people can assert their own identity.

I am so envious of my friend that he can come and go. I am jealous of my friends. I get depressed by it all. I am living in a bubble. (1)

Relying on family means you are not in the driving seat. (10)

No spontaneity a lot of planning. (9)

I couldn't change plans or change time of collection There was still a reliance on family and that I couldn't do everything myself. It did wrangle with me for a while. (3)

I always planned ahead. (4)

Nothing spontaneous. No decisions were ever spontaneous, my autonomy is gone. (12)

The participants have highlighted how important it is to have a flow and autonomy in their life. This section has also demonstrated the level of planning it takes to arrange something when you are relying on family members, and how the lack of freedom and personal autonomy takes a personal toll.

2. Choices

Without a PA service, it can be difficult for disabled people to have opportunity to express themselves and make choices about how they live their life.

For those participants with limited PA hours and still living at home with their family, they expressed how hard it is to ask for help and to tap into their potential.

I hate saying 'I can't do that; can you help me'. Its hugely difficult - I have to swallow my pride. It's very difficult to ask for help. (12)

Sometimes I feel like I can't have a proper relationship with my mom as it [the relationship] is so consumed with my needs. (1)

Before I knew about the PA service, I didn't know that I could have some control over my life. (9)

I can't tap into my potential without the help from a PA. (1)

In addition, other participants who are still based at home, have already seen the benefit of having a PA.

Having PAs in the house to do my personal care allows me have a "normal" daughter-mother relationship, rather than daughter-carer or carer-recipient. It strengthened my relationship with my mother. (10)

You have to keep them [Family] involved in your life. That's not a bad thing. I wouldn't have enough pa hours to live independently so I need their support in the evenings. (8)

However, some individuals, who have access to a personal assistant service, indicate how this service has enabled them make life choices, become involved equally with their family and contribute meaningfully, although the change may have been difficult at the start.

I am employed and make my way in the world as a result of PA service. (2)

I wanted to be fully involved in rearing my children, that's when I knew we needed independent help [PA] so I could play my part. (3)

When I was pregnant - that's when I asked for help. (7)

The PA service enabled college and employment for me... although in hindsight a more gradual move would have been better. (4)

I have more freedom, more choice and more control. (3)

It was easier to introduce the use of a hoist with my PAs. (4)

The PA service enables my child live a normal life and not with the expectation they have to support me. (6)

Others interviewed, who have older parents, appreciate being able to support them in response to the tasks they now need assistance with - which would be part of the normal life cycle; and their PA service enables them to do this.

Being able to support them now is so important to me and I need my PA to do that. (5)

I am very close to my mum now and I can give something back to her in an emotional way. (4)

There was one participant, who now has a comprehensive PA service, has managed to never rely on family members and, and this is a principle they would like to maintain.

I understand the complexity of family. My family is my family and the contract [I have with them] is not for them to care for me. (2)

This section has illustrated how although all the participants strive to live an independent and fulfilling live with their family members, the PA service has enabled them make life choices, which otherwise may not have been possible.

3. Compromise

When disabled people talk about their daily life, they describe how they continually have to balance their needs with those who are providing support to live independently. This section reflects how the degree of compromise can be reduced when a reasonable PA service is available.

The dilemma that disabled people find themselves in when relying on family members for support was articulated by several participants, when PA service was not available to them. The sense of continually living with compromise, and not experiencing personal autonomy are captured by the following quotes from participants about their lived experience.

I never felt I could have a dramatic argument with my parents as I need them to get me ready for bed. (1)

I have to fit my PA around my mums schedule... I might have a shower once every fortnight or 10 days. That makes me very self-conscious. (1)

I wouldn't have asked for as much baths or showers as I wanted. (5)

In family relationships you have to negotiate - you can't demand. (2)

I wasn't used to asking. You know I was just used to doing. It's very hard to ask. That was extremely difficult. You are beholden their time schedule. So, you go back into your shell. Makes me feel alone and isolated. (12)

Sometimes even now I might go without something, because I don't want to listen to a list of moans.... Easier to wait for PA to come in and ask them. (6)

It's hard to get the balance right with all the different relationships. (8)

If you are relying on family members, you have to suit them, and go to their schedule. (10)

There have been occasions when participants experienced a reduction in their PA hours which resulted in increased reliance on family members after a period of independence. As well as being a difficult experience for the individuals involved it also resulted in a changing dynamic and increased stress within the family.

He [my husband] ended up with increased anxiety and panic attacks and back problems. (7)

For those with a PA service, although the act of compromise is always there, there is a gradual adjustment as relationships and roles are established.

There will always be bad days... For the most part I have been able to work it out with family and PA support. (3)

It [Living independently] was difficult in the beginning, but once my mother could see I was safe and able to look after myself... things improved. (2)

There is always compromise when you need support – different type of compromise with family than PA, as the PA will take your instruction. (8)

The way you ask for things with your family is different [from a PA] - as with family although it [the support] may be flexible but, it is on their terms. (4)

The PA service enabled me being more independent and not needing support from my family. I think my family liked to feel needed and they thought they were doing something important. You end up feeling guilty about your freedom. (11)

It is evident from these quotes, that there is an ongoing dynamic and compromise required, as different milestones are reached in the lifecycle of a disabled person.

4. Privacy

Building on the theme of needing to compromise, the lived experience of relying on support from family members brought to the fore issues relating to how boundaries and relationships need to be constantly managed. It also surfaced the mechanisms that people use to protect their privacy.

The baseline of 'expectation of privacy amongst disabled persons' was articulated well by a participant in the focus group who noted that when compared to non-disabled persons, disabled people don't have privacy.

I suppose really, we don't have privacy. Like your PA has to know certain things to allow them do the job properly especially if they do intimate care. You can't afford to be prudish. I suppose the PA allows some privacy from my family but it's not the privacy that a non-disabled person has. (10)

Coming from that low base, the issues relating to privacy are complex. Those with a PA service, indicated how through experience, how they have managed to balance their independence whilst addressing privacy and boundaries in their lives.

On a day-to-day basis I am more comfortable with my PA assisting me than my husband. They do all my business and medical stuff. Every now and again we take a break from PA just to be on our own. (5)

We have made the conscious decision that we have the weekends to ourselves, and use the PAs Monday to Friday. (4)

Negotiating privacy and boundaries with spouses, partners and friends is required when PA service is being introduced. This requires effort and energy from the disabled person to maintain the equilibrium.

I would be very respectful of boundaries. It was hard when I was living at home and bringing a PA into their house. One of my parents is a very private person. So, bringing someone into their house was something we had to get used to over a period of time. (4)

My mother doesn't like people coming into the house - 90% of PA hours are spent outside unless my mum is away. (1)

Even my wife struggled with having someone in the house for more time and working closer with me than anyone else. She was kind of wondering where she would fit in. (3)

Some of my friends struggled when I introduced a PA – they found it hard to get used to them being around. They felt they couldn't meet me if my PA was there. (3)

Whilst it was acknowledged that having a PA did give some privacy from their family, and allowed them to be more autonomous, the governance linked to some PA services could mean that every task a PA carried out had to be accounted for which would generate another layer of restriction.

If I ever want to do something private, I will get my older brother. (9)

Having enough privacy in our lives, enables emotional and physical wellbeing and generates a sense of safety. These examples illustrate the challenges, complexity and compromises that disabled people face to achieve a level of personal privacy and autonomy.



Summary

The lived experience of those who participated in this research identified how availing of a PA service, enabled them have fun with their family as well as being able to live spontaneously without having to plan too far ahead. Those with a limited PA service indicated the effort it took to plan events and how inhibited they were when relying only on family members or friends for support, and they also noted that it was difficult to find out about the services available to support their autonomy.

When approaching key life milestones or events, the absence of independent support inhibits the choices available, and curtails options for disabled people. In contrast, disabled people who have access to a PA service describe how this access enables them to express themselves, and assist them to navigate their career and education ambitions, as well as make choices with regard to growing their family.



The balance of compromise will always be an issue for disabled people as they rely on assistance for their independence, however the availability of PA service allows more accommodation and control; whereas the absence of a PA service constricts and compounds the quality of life and autonomy on the individual, and also their family.

Privacy is something that is very hard for disabled people to attain and the issues relating to privacy are complex and differ amongst individuals. Those with a PA service articulate how they work hard to balance their independence whilst addressing their privacy issues. This balancing act is harder for those with a limited PA service, as they have to share more of their life with their family, when compared with their non-disabled peers.

Recommendations

This research sought to enable disabled people share how the lack of independent living choices, resulting in a reliance on family members, has impacted on their lives. This research has highlighted the restrictions that disabled people face when they have to rely on their family. It also indicates how PA service can open up opportunities for self-determination and autonomy for a disabled person.

The recommendations below seek to address mechanisms to counter the challenges the research encountered.

Disabled People

1. Increase opportunities to raise awareness of the positive impact a PA service can have on personal autonomy and self-determination.
2. Provide support to disabled persons to assist them identify and navigate PA services available.

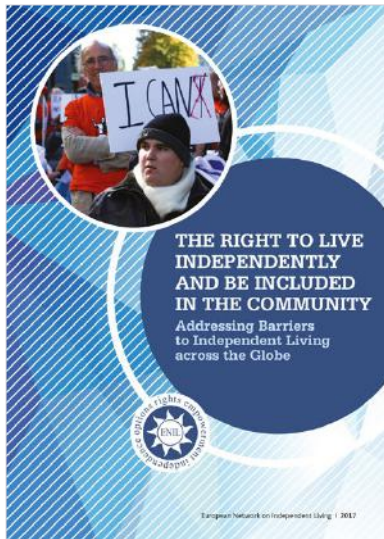
Family members

3. Create opportunities for family members to enhance their understanding of the positive impact a PA service can bring to disabled person and family life.
4. Engage with DPOs to learn more about how PAS can and does liberate disabled people to take control over their lives.

Policy makers and politicians

5. Design in conjunction with Disabled Persons Organisations (DPOs) a national Personal Assistance Service.
6. In conjunction with DPOs define clearly what a PA service is based on the philosophy of independent living.
7. Ensure that there is a standardised assessment for PAS based on the social model of disability, and led by disabled people to express the supports they need inside and outside the home.
8. Invest in a comprehensive PAS system that gives disabled people choice and control over their lives based on their individual needs.
9. Promote PAS as a means for disabled people to express themselves.
10. Legislate for a right for disabled people to access a Personal Assistance Service.

References



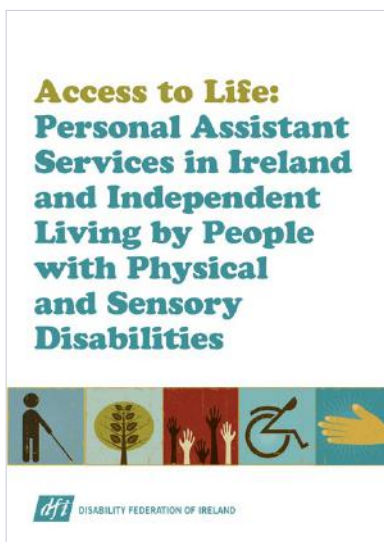
ENIL The Right to live independently 2017

<https://tinyurl.com/2p9dwwcx>

(Accessed 8 July 2021)



Click on the timage to go directly to report



DFI Access to Life: Personal Assistant Services in Ireland and Independent Living by People with Physical and Sensory Disabilities 2014

<https://tinyurl.com/475fmzts>

(Accessed 8 July 2021)



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Anna Dunér and Elisabeth Olin (2018) Personal assistance from family members as an unwanted situation, an optimal solution or an additional good? The Swedish example, Disability and Society, 33:1, 1-19, DOI: 10.1080/09687599.2017.1375900

Informal support is very important and needs to be encouraged. However, the lack of other support options and the exclusive reliance on family can have an adverse effect on disabled people's independence and inclusion.

ENIL The Right to Live Independently 2017





Nothing about us without us

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