

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



DISABILITY FEDERATION OF IRELAND



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



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Acknowledgements

As a post-retirement project on leaving employment at the Disability Federation of Ireland, it was agreed that I undertake this research.

I am grateful to senior staff members from a range of service provider organisations for sharing their perspectives on the Personal Assistant (PA) service, and in many cases introducing me to people using PA services. Thank you also to the educators, advocates, research and policy professionals who discussed the issues with me. Most importantly, I would like to thank in particular, the people with disabilities who agreed to participate and who gave so willingly of their time and their experiences to this research.

A Project Steering Group guided and assisted in progressing the research, and their support was indispensable. The members were:

- Eugene Callan, Leader
- Claire Crehan Dowdall, Irish Wheelchair Association
- Eileen Daley, Leader
- Gary Lee, Center for Independent Living
- Martin Naughton, Leader
- Joan O'Connor, Disability Federation of Ireland

Any value attributable to the report is due to the contributions of the many Leaders who participated.

The Center for Independent Living gave assistance in facilitating contact with many of the leaders interviewed and their work and support merits special acknowledgement.

Lillian Buchanan



Foreword

‘Social justice’ means ensuring that everyone, no matter who they are, or where they live, has the opportunity to develop, be self-determining and participate positively in the community. The barriers that deny social justice for people with disabilities are well recognised – ignorant attitudes, inaccessible facilities, inappropriate and inadequate services and supports. Our Taoiseach and Tánaiste acknowledged these barriers when, late in the 2011 election campaign, they each named disability as their key social policy priority.

The opportunity to become self-determining and a full citizen is about ensuring that the person with impairments has access to supports that enable them to take charge of their life, to engage with the world as they see fit. The Personal Assistant (PA) service, pioneered by a group of individuals with physical disabilities two decades ago, is an empowering initiative, giving the person with disabilities control over any assistance they need to go about daily life. Those pioneers pre-empted the Government’s policy objective outlined in the National Disability Strategy, of “maximising independence and self-reliance and integration in the mainstream”.

This research on the PA service contributes to DFI’s own mission which, is “to act as an advocate for the full and equal inclusion of people with disabilities and disabling conditions in all aspects of their lives^a”. We are acutely aware of the serious difficulties imposed on people with disabilities by the serial cutbacks in the deficit reduction programme. Since an effective Personal Assistant service is a critical part of the social justice infrastructure, as it enables people with disabilities to participate in society as citizens, the way the PA service has fared is an important indicator of policy performance. This research looks at the situation of the PA service today in Ireland, particularly from the perspective of those using the service, the Leaders. One of its main findings is that the quality of the PA service has been eroded over time. This is an alarming finding meriting serious debate.

The report would not have been possible without the support of many individuals and organisations, including the Center for Independent Living and the Irish Wheelchair Association who arranged numerous opportunities for discussion with those most involved with the service. It is our hope that the various contributors will use the research report to advocate for a stronger PA service in Ireland. Thank you to the people with disabilities who participated, whose experiences have greatly informed this research and will enhance the on-going discourse on the future direction of the PA service.

Maurice O’Connell
Chairperson, DFI

a See DFI website at: <http://www.disability-federation.ie/index.php?uniqueID=7>



**“Restoring the
focus on enabling
independent living”**

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Executive Summary



THE RESEARCH

The report looks at Ireland's Personal Assistant (PA) service, a service for people with significant physical and sensory disabilities that is mainly funded by the Health Service Executive (HSE). The study aimed to explore the meaning of the 'PA service' today, its key positive features, and the ways in which these features could be protected and strengthened.

The research involved a review of policy documents as well as interviews with a range of stakeholders to gain their perspectives on the evolution of the service. The core work consisted of one-to-one interviews with thirty people using a PA service. These individuals were of different ages, lived in different parts of the country and had different types and degrees of disability. The interviews focussed on each person's experience using the service to pursue a full and active life.

The findings reveal the views of thirty people using PA services who have embraced the notion of independent living and the distinction between a carer service (managed by the provider) and a PA service (largely managed by the Leader/user). The research demonstrated that the PA service is vulnerable to funding cuts and inappropriate forms of regulation due to – as is evidenced in the research – a lack of a shared understanding of its special role and purpose. Although the PA service facilitates mainstreaming and the “full inclusion and self-determination for people¹”, which is the Government's stated objective for disability services, it has largely been ignored by policy makers evaluating disability services².

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- 1 Excerpt from the first policy goal stated in Department of Health (2013) *Value for Money and Policy Review of Disability Services in Ireland: Implementation Framework*; 5
 - 2 For example, see Department of Health (2012) *Value for Money and Policy Review of Disability Services in Ireland*.

DEFINING PERSONAL ASSISTANT (PA) SERVICE

The small group who established the PA service for themselves and others in the early 1990s had a clear appreciation of what the service was about, namely self empowerment to overcome the disadvantage imposed by physical and sensory impairments. The service recipient did not just receive a particular number of hours of a PA's time; rather he/she worked as a Leader, directing the PA's activities so as to maximise their own life opportunities. The Leader's capacity to manage the service was underpinned by collective training initiatives for Leaders and their PAs, as well as networking amongst other Leaders.

Since then, the empowering concept behind the service has been weakened, the interviews revealing that many new entrants to the service have less control over their service. The service came under stress when the Government took over funding responsibility in 1994 and the administration and training aspects became the responsibility primarily of a voluntary service provider organisation. Subsequently, the emphasis has shifted to providing for basic personal care needs, such as dressing and toileting, with less attention to supports for independent living. With the arrival of austerity, funding for the service has decreased. Evidence from the research demonstrated that the prioritisation of care provision over so-called social support has increased, and the meaning and understanding of a PA service has therefore, been further diluted.

SERVICE EXPERIENCE

Each of the thirty people using PA services who were interviewed fully appreciated the difference between a care service and a PA service and each considered him or herself to be a Leader. Although their scope to manage the service varied, the interviewees all linked their leadership role to an improved quality of life and fuller participation in society. Service features named as key included power over PA recruitment, primary responsibility for PA training, and responsive supports when human resources or other intractable problems surface. Appropriate and fair pay and conditions for PAs as well as sensitive health and safety regulations were also cited as critical, given that the role of a PA requires flexibility and inter-personal skills.

Comparing experiences across the thirty interviewees reveals a difference in the empowerment aspect of the service, which was related to when a Leader first obtained the service. Not only were more recent entrants likely to have less PA hours to manage but they also seemed more apprehensive about the future. They worried about the level of their service being sustained; about getting increased hours when their condition worsened or if they wished to leave the parental home.

In summary, the research found that the original model of the PA service established by the pioneers has been undermined. Restoring the focus on enabling independent living, as well as covering basic care needs, would strengthen the service's effectiveness

for progressing the Government's policy objectives. It would enable service recipients to pursue meaningful lives as they so determine, and to continue extending mainstreaming in the footsteps of the pioneers from two decades ago.

Recommendations

The recommendations detailed under section 5.2 stem from the research, and are listed here as follows:

RECOGNITION FOR THE PA SERVICE

1. The Department of Health should lead in further developing the definition of the PA service so that it encompasses equality-based independent living, as reflected in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).
2. In keeping with Article 19 of the UNCRPD, the Department of Justice should examine the case for establishing the PA service on a statutory basis as one of the supports enabling disabled people to participate as full citizens.
3. The Department of Health should commission an independent, holistic evaluation of the service, including social as well as economic costs and benefits.
4. Since the PA service is exceptional in how it facilitates social inclusion, the government, especially the Department of Public Expenditure and Reform should explore new ways of funding the service. A national disability insurance scheme similar to that introduced in Australia could ensure secure funding. Another possibility is the establishment of an 'Independent Living Fund'.

PA SERVICE PRACTICE

5. The HSE urgently needs to engage with Leaders and others in the disability sector to clarify what constitutes a PA service and to put the agreed definition into practice. Pathways to direct payments, where a Leader can become the employer, also need to be developed, based on learning from international as well as Irish experience.
6. The HSE's assessment process must incorporate the independent living activities named by the applicant. The association of independent living with improved well being and happiness is well accepted as relevant to our public health goals.

7. Leaders should have options about how they use the PA service, regarding the extent of responsibility they take on and on the needs they have for the service. Any HSE commissioning/tendering process must focus on each person achieving independent living, not just on general aspects of service provision.
8. With the ageing of the pioneer Leader cohort, disability organisations need to be innovative in engaging with people and supporting their networks. The HSE also has a role in supporting voluntary self-help. For example, information about the PA service needs to be improved.
9. The development of any HSE and Health Information and Equality Authority (HIQA) standards and regulations for the service should be co-developed with Leaders so that Leaders can influence and have a sense of ‘ownership’ in this process. Changes to employment regulations should be explicitly evaluated in the context of home-based work.

JOINED UP WORKING

10. A rigorous evaluation of the likely impact of any proposed policy changes on the UNCRPD’s Article 19 commitments is essential and must be evidenced in the Government’s National Disability Strategy Implementation Plan.
11. The co-ordination achieved to date under the National Disability Strategy has been disappointing; performance by government departments and agencies needs to markedly improve.

DEVELOPMENT OF THE PA SERVICE

12. Given the rapid pace of change in the area of policy on personal supports and independent living, it makes sense for the Disability Federation of Ireland or another voluntary disability organisation to repeat this review of Leader experience a few years hence.



Chapter 1:

Introduction and Background

1.1 Introduction

The Disability Federation of Ireland (DFI) understands that the service of a personal assistant (PA) is essential for many people with disabilities if they are to pursue quality lives in society. Moreover it is the service within the HSE's Disability Programme that reflects the modern approach to disability, epitomising independent living and participation. Despite being aligned with the government's over-arching public policy objective, however, the service today is very vulnerable. The funding cut announced in August 2012 (subsequently withdrawn following vigorous protests) is symptomatic of the absence of a shared understanding, within the HSE and beyond, about the purpose and value of the PA service³.

This report looks at personal assistant (PA) services in Ireland, and presents qualitative research exploring the experience of people with physical and sensory disabilities who are Leaders in using the service⁴. It seeks to address a number of questions:

- What constitutes a PA service, as viewed from different perspectives?
- What is the value of the user/Leader being able to direct the service?
- What factors may shape the service in the future?

The report aims to promote a better understanding about Ireland's PA service, and why it merits respect and support. The current state of the service is examined, as reflected in national policy documents and feedback from stakeholders, and importantly, in consultation with people actually using the service. In addition, the way the service contributes to the realisation of "full inclusion and self determination for people" is explored with those users/Leaders⁵. The focus is on the fit between the government's stated disability policy objective and practice as it is evolving on the ground.

3 DFI calculated that the cut would, if implemented, have effectively withdrawn the service for the remainder of 2012.

4 See Appendix 2 regarding the 'Leader' concept.

5 Excerpt from the first policy goal stated in Department of Health (2013) *Value for Money and Policy Review of Disability Services in Ireland: Implementation Framework* page 5

1.2 Why this Research?

A PA service has existed in Ireland for more than twenty years, during which time knowledge about disability has been developing in line with the ethos inherent in the service.

As members of the disability movement see it, the Personal Assistant service contributes to realising human and civil rights, and the expectation of equality of opportunity for all members of society. PA service is an integral component of equality by facilitating independent living. It helps to level the playing field for those with significant impairments and promotes a move towards a more 'disability friendly' environment and social culture, without access barriers and attitudinal constraints.

Meanwhile, the HSE has recently defined a PA service as follows:

'A Personal Assistant is employed by the person with a disability to enable them to live an independent life. The PA provides assistance, at the discretion and direction of the person with the disability, thus promoting choice, and control for the person with the disability to live independently'⁶.

The modern approach to policy, whereby disability is seen to result when society fails to address the barriers that exclude, now underpins government's social policy strategy⁷. For example, in 2004 both the Taoiseach and the Minister of Finance prioritised the allocation of extra resources to home support and personal assistance for persons with physical or sensory disabilities, setting up a multi-year investment package⁸.

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- 6 As per the National Physical and Sensory Disability Database definition contained in HSE (2013) KPI Metadata 2013 Disability Services.
 - 7 For example, Department of Environment, Community and Local Government (2011) National Housing Strategy for People with a Disability 2011-2016; HSE (2012) New Directions: Review of HSE Day Services and Implementation Plan 2012-2016. Personal Support Services for Adults with Disabilities; Department of Transport (2008) Transport Access for All: The Sectoral Plan for Accessible Transport under the Disability Act 2005; Department of the Taoiseach (2006) Towards 2016: Ten-Year Framework Social Partnership Agreement 2006-2015.
 - 8 Speech by the Taoiseach at the launch of the National Disability Strategy in the Alexander Hotel, 21 September, 2004 in which he stated, "We want public policy for the future to be based on an understanding of disability that is described as the move from the medical model of disability to the social model. This will encourage a series of actions [including] maximising independence and self reliance and integration in the mainstream wherever possible..." See also Minister of Finance, Budget 2005 Speech, page A16, where funding for extra hours was announced "in line with the philosophy of supporting independent living".

The 2011 Programme for Government promises to ratify the UN Convention on the Rights of Persons with Disabilities, which in Article 19 names the right to supports for independent living.

Nonetheless, the PA service has not been recognised and respected as integral to this modern approach. Instead, information about the service remains inadequate; delivery differs depending on where one lives and what organisation acts as the provider. Funding has been squeezed. Only recently did the HSE begin to define what constitutes a PA service⁹. Furthermore there has been no published evaluation of the PA service by government, and this area was by-passed in the major Value for Money and Policy Review report that is to guide future policy and practice¹⁰.

An orphan in Ireland's social policy framework, the PA service's future is especially precarious in an environment of persistent budgetary austerity, combined with transformations in the public health and social care system. The HSE's intention to focus on the PA service as one area for consideration in a tendering process, along with home support services for people with disabilities, could result in substantial changes in the opportunities available to people with significant physical and sensory disabilities. It is therefore vital to learn about the nature and value of the PA service, as it is now.

There are other reasons why an exploration of the PA service at this time is necessary. Increased demand for personal support services is likely as people with disabilities move from institutions into the community. At the same time there will be demand for additional services as people's expectations rise, and as they live longer. Innovations that develop the potential of the service via direct payments, focus attention on the role of the user in managing personal services¹¹. Public policy commitments to support independent living should also influence future development.

If Irish disability policy really is to advance to the professed goal of social inclusion, a strong PA service must be part of the infrastructure. It is important to evaluate the nature and scope of the PA service as it currently exists in the context of current disability policy strategies and statements. This research attempts to throw some light on the actual practice by facilitating those using the service to 'tell it like it is', so that policy makers and implementers can better design their interventions to achieve agreed public objectives.

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- 9 In 2013 the HSE announced it would be using the National Physical and Sensory Disability Database – Description of Services, definition contained in the HSE's *KPI Metadata 2013 Disability Services*, available at <http://www.hse.ie/eng/services/Publications/corporate/performance-reports/KPI%202013%20Disability.pdf>
 - 10 It is understood that the Department of Health commissioned an evaluation in 1995 but no report was published.
 - 11 Áiseanna Tacaíochta is one example of where innovative work is taking place. www.theatnetwork.com

1.3 Research Methodology

The research uses qualitative research methods, grounded in the experience reported by a range of users of the PA service who describe themselves as Leaders. The research began in late April and the report was finalised in December, 2013. A Project Steering Group, consisting of Joan O'Connor, Disability Federation of Ireland, Gary Lee, Center for Independent Living, Claire Crehan Dowdall, Irish Wheelchair Association and Leaders Eileen Daley, Eugene Callan and Martin Naughton advised on the research and commented on drafts of the report¹².

1.1.1 QUALITATIVE INTERVIEWS

The core research involved one-to-one interviews with individual Leaders. Thirty persons living in the community with physical and / or sensory disabilities participated. A combination of purposive and snowball sampling was used to access potential participants¹³.

The criteria for inclusion in the research were that participants:

- were of working age.
- had significant physical and / or sensory disabilities requiring support for basic living activities.
- considered themselves to have a PA service.

The interviews represent the views and experiences of individuals of different ages and with different types and degrees of disability.

12 Members also gave essential assistance in identifying possible Leaders to participate in the research.

13 Purposive sampling is a form of non-probability sampling in which decisions about who to include in the sample are taken based upon a variety of criteria, which could include specialist knowledge of the research issue, or capacity and willingness to participate. This research necessitated the researcher making decisions about the individual participants who would be most likely to contribute appropriate data. Snowball sampling is a non-probability sampling technique used where it may be difficult to locate participants. The researcher asks participants to provide information on other potential participants from within that population.

The one-to-one interviews were conducted with persons living in each of the HSE's regions, and generally lasted for about one hour. More than 70% of the interviews were face-to-face meetings, sometimes with a PA present to assist communication. The conversations were treated as strictly confidential. Further information about the research design is in Appendix 1.

1.3.2 PROFILE OF INTERVIEWEES

AGE CATEGORIES OF LEADERS	30 LEADERS
20-35 years	7
36-60 years	20
61+ years	3

NO. OF YEARS WITH AN IRISH PA SERVICE	30 LEADERS
5 years or less	8
6-10 years	7
11-18 years	6
19 years +	9

LIVING SITUATION	30 LEADERS
On my own	20
with my parents	4
with my spouse / children	6

The sampling techniques used gives reasonable confidence that a range of perspectives on the issues have been included:

- Leaders from every region of Ireland participated although those living in rural areas, outside of towns or villages, were few in number. Fifteen lived in Dublin or within its commuter belt.
- Seven participants were aged under 35 years, twenty were of working age and the remainder were aged over 60, some of whom had taken early retirement on medical grounds.
- Thirteen women and seventeen men participated.
- Twenty lived alone although several of these Leaders had a PA or carer staying over. Four lived with their parents while six Leaders shared their home with a spouse and / or children.

One focus group discussion was organised by Offaly Centre for Independent Living with participation by six Leaders (one older Leader, and five younger Leaders).¹⁴

1.1.3 INTERVIEWS WITH OTHER STAKEHOLDERS

The researcher also held informal interviews with senior staff in eight PA service provider organisations. One senior HSE official was interviewed, as well as 3 people from the advocacy, education and research sectors, and 6 individuals from voluntary disability organisations.¹⁵

14 None of the Offaly participants participated in one-on-one interviews.

15 One from the National Advocacy Service (NAS), one from the National University of Ireland, Maynooth, one HSE retiree, as well as 6 people from voluntary disability organisations.

1.1.4 DESK-BASED RESEARCH

The project also involved desk-based research to gain an understanding of national policy regarding the PA service.

In addition the researcher attended an event organised by the Center for Independent Living (CIL) Carmichael House on the drafting of a “Personal Assistance Service Bill”.

A schedule of topics was developed to guide the one-to-one interviews with the thirty people receiving the PA service. Please see Appendix 1 for further information.

Research findings were analysed using the grounded theory approach, where key concepts were generated to explain the research participants’ experiences of the PA service and of their efforts to address their concerns with the service. The researcher produced field notes from each interview, which were used to generate concepts that corresponded with the data, and with other participants’ perspectives.

The 30 Leaders who participated in the research received a copy of the draft findings and their comments were incorporated into the final report.



Chapter 2:

The Social Policy Context

2.1 Introduction

This chapter firstly explores the evolution of the PA service in Ireland, and then reviews the policy context from a public policy perspective, as well as from the perspective of stakeholders.

2.2 Early Evolution of Personal Assistant Service in Ireland

In the early 1990s a small group of people with significant physical and sensory disabilities pioneered the Personal Assistant (PA) service in Ireland, using EU and FÁS funds to finance a ‘pilot’ scheme, called INCARE. Spokespersons described this initiative as action research whereby they learned by doing. The employment of PAs was to support independent living by adults who had previously been resident in institutions or parental homes. A key feature of the service involved the person with the disability directing the PA’s work. Training and peer support arrangements, including establishment of the first Center for Independent Living, (CIL) were integral to the pilot programme. Leaders recognised the value of the PA role, ensuring that the workers accessed training and certification.¹⁶

After 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.¹⁷ When the Eastern Health Board took over in 1994, funding was based on the cost of the supports for each INCARE participant, which in turn was based on the person’s own assessment of their needs supplemented by advice from their CIL. The Irish Wheelchair Association (IWA) was contracted to run the service rather than continuing with the CIL. Those people who had set up and benefited from the pilot initiative were thus safeguarded in this transition but the government did not at this time articulate a policy position on the new service.

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16 The Centre for Independent Living commissioned the *Evaluation of the INCARE Personal Assistance Service Programme* by Grainne McGettrick which was published in 1994.

17 The protest lasted 36 hours until the government agreed to act.

Outside Dublin independent CILs soon were established using FÁS funding under the Community Employment (CE) scheme and later health funding was received to pay for PAs. Negotiations late in the decade to transfer responsibility from FÁS to the health authorities broke down, and FÁS's role in relation to the delivery of the PA service tended to diminish as restrictions on the CE scheme tightened.¹⁸ Nonetheless a number of CILs still rely on CE training to provide PAs, supplementing HSE-funded support.

The independent living movement's vision of PA service continues to underline the right of Leaders to supports for developing their lives, and the right to choose the way and the extent to which they take on management responsibilities. An attempt to summarise the movement's perspective is set out in Appendix 2.

2.3 Policy Relating to the Personal Assistant Service

This section considers the national policy context for the PA service and then goes on to explore the policy perspectives of other stakeholders to the service. The aim in this section is to learn about the achievements and challenges of the service, from a national policy perspective. The perspectives of other stakeholders are included here at the juncture of national policy and the perspectives of Leaders discussed in Chapter 3.

2.3.1 THE HSE'S APPROACH

During the mid-2000s the National Disability Strategy prioritised the expansion of personal care hours.¹⁹ However, the HSE at this time did not specifically identify the PA service, referring instead to 'PA / Home Support' service (i.e. including provider-managed care service).²⁰

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- 18** A Leader observed that the FÁS-based service was never regarded as a long-term solution because trainees had only temporary placements
- 19** The Minister of Finance announced in 2004 an extra 1.2 million hours for home support and personal assistance as part of the Multi-Annual Investment Package for Disability. See: Minister of Finance, Budget 2005 Speech, page A18.
- 20** The Department of Health and Children published its Sectoral Plan under the Disability Act 2005: Year 1 Review which stated, "The protocols governing the implementation of, and reporting on, the Multi-Annual Investment Programme for services for people with disabilities detail specific targeted areas for which funding has been announced. These include...Residential and home support / personal assistance services for people with physical and sensory disabilities..." (page 20/21).

Although a considerable funding increase was reported from 2006 to 2008 (inclusive), there is no evidence available of any government evaluation of what was achieved from this investment.

Spending trends since 2008 undoubtedly were affected by the government's over-riding deficit reduction priority. In some regions committees consisting of providers and health officials (but not those with disabilities) allocated any resources freed up due to deaths and other changes. Basic care needs had priority. Although the latest HSE application form for a PA service refers to 'social' needs, the focus is strongly on reporting the times required for such basic functions as getting out of bed and toileting.

Unfortunately none of the national statistics generated to date, whether from the HSE Key Performance Indicators (KPIs) reported in the HSE's National Service Plan, the National Physical and Sensory Disability Database (NPSDD) or from the Value for Money and Policy Review of Disability Services, can be regarded as reliable measures of PA service activity (Appendix 3). Indeed the HSE, following an investigation in 2012, identified new KPIs to be reported from 2013. These distinguish between PA and care services for people with physical and sensory disabilities as well as adding such services for other kinds of recipients. Definitions for the PA service and Home Supports have been set out in the HSE's KPI Metadata 2013 Disability Services.²¹

2.3.2 POLICY DIRECTION FOR THE PA SERVICE

Key policy documents relating to the PA service are discussed here. First, the current government has promised to ratify the UN Convention of the Rights of Persons with Disabilities (UNCRPD) which in Article 19 contains a strong commitment to independent living for all people with disabilities. Ratification, therefore, should promote endorsement and expansion of a leader-led PA service.²² However, 'Future Health – A Strategic Framework for Reform of the Health Service 2012 – 2015

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- 21** A Personal Assistant is employed by the person with a disability to enable them to live an independent life. The PA provides assistance, at the discretion and direction of the person with the disability, thus promoting choice, and control for the person with the disability to live independently. (National Physical and Sensory Disability Database – Description of Services).
 - 22** The Programme for Government published in 2011 states on page 54, "We will move a proportion of public spending to a personal budget model so that people with disabilities or their families have the flexibility to make choices to suit their needs". This is not the same as an endorsement of direct payments or a PA service to enable independent living.

(DoH, 2012), the latest Department of Health strategic framework document outlines plans that do not appear to be entirely consistent with the Convention or the disability movement's vision. Neither the Value for Money and Policy Review of Disability Services in Ireland nor the subsequent National Implementation Framework specifically address the role of the PA service, although the first goal named for Disability Services is:

“Full inclusion and self-determination for people with disabilities through access to the individual personal social supports and services needed to live a fully included life in the community”.²³

Moreover the government's ‘National Disability Strategy Implementation Plan’, released in July 2013, makes no mention of Personal Assistance, despite naming high level policy goals that reflect independent living.

Changes outlined in ‘Future Health’, and their implications for people with disabilities, include:

- People will be subject to a standard needs assessment for determining their eligibility for a service but they do not have a statutory entitlement to that service. Thus it is expected that budgetary movements will shape the eligibility criteria applied. In particular, the care needs essential for avoiding institutionalisation may well emerge as the over-riding priority. The National Disability Authority is currently researching assessment models.
- Disability and older people's services in the HSE are being combined in the new organisational structure. The needs of working age adults, who rely on specific disability as well as mainstream services to build their lives, may struggle for attention.
- A strategic commissioning model is to be developed and used to procure services. In the case of personal disability services, a senior HSE official who participated in this research commented early in 2013 that tendering for services, specified after wide consultation, is likely to be the route taken.²⁴ It was noted at this time that the HSE intended to consult stakeholders about defining specifications for different types of personal support services, with a ‘pure PA service’ at one extreme and a basic care service at the other extreme. The HSE

23 Department of Health (2013) Value for Money and Policy Review of Disability Services in Ireland: National Implementation Framework; 5.

24 Seminar on Tendering, held in DFI in January 2013. See also: HSE National Operational Plan 2013, page 64.

envisaged pay for the pure service to be around the current rate for PAs which would then graduate down to the minimum wage for the most basic care. The alternative of direct payments to Leaders to pay for their PA service does not appear to be on the government's near-term agenda.

- “Primary legislation and resources will be required to introduce a statutory regulation system for the home care sector”.²⁵ The ways in which the highly individual requirements for PA work will be incorporated into the system remains to be seen.
- The extension of ‘Fair Deal’ and means-testing for services is also being considered. This would imply charging people for services that simply give them a degree of equality with those who are not disabled.

Given these government plans, and the constraints on the service over the last five years, those concerned with protecting a leader-managed PA service are engaging actively with policy makers. Centers for Independent Living (CILs) and the Leaders’ Alliance advocate for the PA service in the context of enabling independent living. For example the Center for Independent Living has been organising the drafting of a “Personal Assistance Bill” that would put the service on a statutory basis.²⁶ The Leaders Alliance has submitted to government a list of the features that an effective PA service must have.²⁷

2.3.3 PERSPECTIVES OF OTHER STAKEHOLDERS

Discussions with service providers and other stakeholders suggest that the HSE, especially since 2008, has made it more difficult for an applicant to demonstrate support needs that reflect their full life agenda.²⁸ The emphasis is on care rather than on enabling the disabled person to take charge of their life. Several commented that

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- 25** Department of Health (2012) Future Health - A Strategic Framework for Reform of the Health Service 2012 – 2015: 40.
- 26** Center for Independent Living held a conference in June 2013 where 40 Leaders and 17 others gathered to discuss the draft legislation. Information about the Bill can be viewed at www.dublincil.org
- 27** See www.leadersalliance.ie
- 28** For the purpose of this research, other stakeholders include service providers, individuals from the advocacy, education, and research sectors, as well as 6 individuals from voluntary disability organisations.

the meaning or definition of a PA service has changed from its original conception, and has been diluted to include assisted care supplementing that provided by family. A bias towards physical care tasks and against tasks that involve assisting participation in social activities appears to have developed.

It was suggested by one provider that this is partly due to the stretching of scarce resources to cover more people, including those with less significant disabilities. Some advocates also wondered if more recent recipients of the service were less 'willing and able' to lead²⁹. A pioneer in the INCARE project said that being a Leader ought to involve the application of skills, a lot of hard work (e.g. organising relief cover, serial PA training, intensive daily management) and a willingness to move out of one's comfort zone to get what one wants.

Another stakeholder identified a fundamental, structural shift which happened when the Eastern Health Board took over funding for PAs in 1994. Before then Leaders were working together to build independent lives using PAs as necessary. When the Board stepped in the situation changed to a PA service provided by an established organisation. Instead of an independent living focus and attention to developing leadership qualities, the focus was on entitlements. With the onset of deficit reduction in 2008, it was suggested that the low profile of the independent living aspect of the service made the paring back of funding easier. It arguably has also made plausible the idea of tendering to allocate the funds. If PAs are seen as not only assisting with basic tasks that the Leader cannot do by themselves, but also supporting the Leader's efforts to take control of their life, then the idea of tendering becomes problematic.

It was also noted that preparation for Leaders to take on responsibilities has become more difficult as the disability movement struggles with peer networking, and government health and safety regulations increasingly dictate how people with disabilities conduct their private life. For example, many newer Leaders lack close relationships with disabled counterparts. Provider organisations taking over Leader and PA training from the collective may have raised the level of bureaucracy and the monetary costs of operating the PA service, according to one advocate. There was also a view that newer Leaders may be afraid to challenge and demand greater control because they fear that their services will be affected.

The views of organisations providing PA services to people with physical and sensory disabilities focused on the challenges for services in the face of increasing demand and recession-driven funding constraints. One of the challenges mentioned was the uncertainty associated with people who are using services ageing beyond 65 years, and their eligibility to continue to receive disability services, which could vary across the regions.

29 One person observed that the Family Resource Centres could be a local, on-going source of support for Leaders.

While all the organisations employed the PAs, there were differences amongst them in how they approached the delegation of management responsibilities to people using services and in acknowledging the Leader role. It was noted that some provider organisations consider all their personal services, no matter how limited the hours and scope for user direction, to qualify as PA services but others now focus on giving the user as much ‘say’ as possible without describing the users as leaders who manage their service.

2.4 Conclusion

The review of policy material and discussions with stakeholders suggests that Ireland’s PA service is under considerable strain, and that the original feature of Leader empowerment through their ability to control their PA service, is being eroded. Since the inception of the PA service by campaigners in the early 1990s, public policy commitments have not become entrenched through for example, detailing what people can expect in practical terms from the PA service. Although the government announced increased funding in 2004 for the PA service, the focus on leadership quickly faded. There did not appear to be ‘buy-in’ to the idea that the key performance indicator for a PA service should relate to the achievement of independent living.

Definitive information on the number of Leaders and the number of PA hours provided is lacking; however, the views of other stakeholders suggest that the net increase in the Leader count has been minimal for some time. Increases in funding prior to 2009 seem to have concentrated on the provision of home care rather than support for fully independent living. New Leaders seem to get less PA support hours than those who had joined the scheme earlier on. The capacity of disability networks to underpin the Leader role has been questioned by a few observers, whether because people didn’t fully appreciate their common interest or because of logistical barriers to working collectively.

The qualitative evidence from the interviews with Leaders as discussed below is a timely contribution to the policy debate, in the context of Article 19 of the UNCRPD, the Value for Money and Policy Review of Disability Services, and of Future Health. The findings are important in the context of the current PA service, as well as for de-congregation, when it is critical that the policy direction points the way forward in independent living and services and supports to facilitate community living.



Chapter 3:

Perspectives of Leaders: Using the Service

3.1 Introduction

This chapter focuses on the perspectives of the 30 Leaders who shared their experiences of using the service, its key empowering features, the challenges involved in managing the service, and the difference the service made to their lives.

3.2 The Service as a Support for Independent Living

The Leaders were asked whether a PA service, by giving the user control, improved their own well-being and thereby benefited the wider community. Differences amongst the Leaders' views on the effectiveness of the service were also explored.

3.2.1 PERSONAL WELL-BEING

Research participants were asked about the effect of the PA service on their well-being. It was clear that the service enhanced the well-being of every Leader, enabling them to participate and to pursue a fuller life. According to a middle-aged, long term Leader:

'When the PA comes, my life starts. When the hours were cut it took a slice out of my life'.³⁰

A young person, also a long term Leader commented:

"If you're only helped to get out of bed, that's no life. It's great when I can't make something because I'm busy, not because I can't get there".

30 This person, who has multiple impairments, is very isolated without the PA, despite living in a small local community. For instance they are unable to read, listen to music or watch TV.

For a third long-term Leader, having a PA:

“...broadened my horizons. I suppose it must be like climbing a mountain. It’s not until you stop and look around that you realise how high you’ve climbed ... and are able to enjoy the view”.

Younger and more recent Leaders explained that:

“I am happier as my PA enables me to socialise, and I can have an ordinary life”.

“When I became a Leader I was a million times happier. Before, when workers were assigned, I became depressed. When I got to choose them myself, it was so important. It’s great to have my own space, and also meet and know people”

Another Leader commented:

“Without the service I wouldn’t be me really”.

The service also provided Leaders with a sense of being equal with other people, which was mentioned by most interviewees, but especially by the younger Leaders. One explained:

“I can be equal because I don’t impose on family and friends”.

Another illustrated this with an example: ‘at my birthday everyone now just enjoys the occasion.’ Another said ‘I can be a regular aunt and sister.’

Some of the long-term Leaders referred to their enhanced ability to support their family; for example, by sharing their home with an elderly parent or by raising their children. A long term Leader summarised:

“Having a PA means you do not have to rely on family for the everyday mundane but necessary tasks. It also means that when you spend time with family it can be quality time”.

3.2.2 A SERVICE EARNED

Most of the Leaders fought hard to get the level of PA service required, with e-mailing, letter-writing and / or petitioning politicians mentioned by most interviewees. A number were working on ways to gain greater control over their service.

For many, campaigning for a fairer society had long been their priority, and this was reflected in their use of the service. Several longer-term Leaders, for example had written books and articles related to independent living while others started up and supported working groups. Giving disability awareness presentations, contributing to training and other forms of engagement were mentioned as well by both younger and older Leaders.

3.2.3 ENABLING SERVICE

The PA service works as an activator and enabler for people to pursue their lives. The following quotes illustrate this aspect of the service:

“It enables me to take the initiative [e.g. my garden, my church]....it’s easy to become lazy [give up] when you’re disabled but PAs help prevent that”. (middle-aged Leader)

“All through my life I work out the next step to where I want to go [e.g. to get an education and later a career]”. (long-term Leader)

“My own initiative has been key to a good life, and PAs facilitate me taking initiatives”. (younger Leader)

“I have freedom of manoeuvre for planning my life”.

“With the PA service it’s liberating and exciting to be normal, being a Dad, and attending my kids’ events”. (long-term Leader who is also a parent)

“I’ve got the right to try and fail”.

3.2.4 USED FOR PARTICIPATION PURPOSES

Almost all interviewees, as well as participants in the Offaly discussion group, were acutely aware of the myriad of ways in which the service enabled them to participate and gain a good quality of life. One young woman who had been a Leader for a short time named a list of advantages made possible by the service, including: 'owning a pet, living on my own without having to move to Dublin [from a distant county] to get decent supports'. She added:

“Because of the PA I can work and I have been able to take night courses”.

Indeed, of the thirty Leaders some thirteen pointed out that they were in full or part time paid employment while a number of others were in training to gain jobs or actively volunteering. One young man devoted more than 25 hours a week to support the local community centre, including engaging with children in the crèche. He said:

“At first they were afraid of me but before the end they were climbing all over me”.

Two others explained how they shared their Information Technology expertise with community groups. One longer-term Leader commented:

“The HSE wants value for money. So they should do a proper cost/benefit study that factors in things such as my contribution as a worker”.

The energies of many Leaders were focussed on the wider community, such as getting a mainstream education, maintaining friendships, supporting neighbourhoods. Participation in society was highly valued, as one middle-aged man pointed out, 'I can go to the sports club and be one of the lads'.

3.2.5 LIMITATIONS OF THE SERVICE

There were some interviewees, primarily amongst the newer Leaders, who felt inhibited because of the number of PA hours available. One older person who had obtained the service quite recently was concerned about the pressure on his partner since the PA hours were so limited. He commented that his wife suffered as a result and he worried for the future.

Another older man who had not been a Leader for long explained that his wife had to provide basic care in the evenings and weekends on top of a full time job. She had no time to herself and little opportunity to take a holiday. Many other Leaders also relied on family and friends to fill in the gaps in support, or they experienced a reduced quality

of life. Amongst the consequences of limited services cited by participants was the serious strain within the family, poorer health and a sense of isolation.

Lack of cover for PA holiday leave was a problem for several Leaders spanning all ages. A new Leader said that she couldn't do her therapeutic exercises without the PA, and suffered as a result. Another explained that they had to struggle to pay for additional PA services in order to do their job. A longer term Leader who was employed full time pointed out: 'I have to synchronise my holiday with my PA's because I can't get to work when she's away.' One Leader suggested that a reserve PA service fund to cover special holidays or other temporary need should be set up.

3.2.6 SUMMARY

All those interviewed linked their ability to enjoy independence to their PA service and the ability to manage their service. The ways they used that independence depended on numerous factors, but many of the Leaders referred to the benefits for themselves, for the wider community as well as for their family and friends. At the same time some Leaders appeared to feel better positioned than others to pursue independent lives, with recent entrants to the service most likely to qualify the empowering impact of the service.

3.3 Responsible Leaders

All interviewees had some degree of ability to manage their PA service. However a significant number who joined more recently were frustrated because of their limited scope to direct the service, despite treasuring what control they did have. Almost all these Leaders explained how they were actively seeking better arrangements. In addition, a few other longer-term Leaders with significant hours reported serious problems in the past that had forced them to take quite radical steps to enable more independent living. Most of the remainder were working with the system even if their PA hours fell short.

3.3.1 MANAGING THE SERVICE

Managing a PA service, including recruiting, training, planning schedules, completing time sheets was considered by participants as a job in itself. As one long-term Leader put it:

"Being a Leader is necessary but it is a hard road to get to where you want to go. I work just to live my life".

Another commented that:

“The Leader role is work but I wouldn’t want to give it to anyone else. It’s part of having a life”.

A younger Leader observed:

“Leadership is stressful at times, but manageable. It’s worth it”.

Most Leaders use PAs to aid them in basic human activities such as dressing³¹. In addition, the service enables them to pursue life, whether this involves getting about, communicating, assisting in work-related tasks, running their home or maintaining their health. Specific special skills may be required, such as catheter handling. Less specialised tasks such as helping with transport, housework and shopping were frequently mentioned. One Leader spoke of the PA preparing ingredients ‘for me to cook meals for my family’. PAs that support a Leader in the work place were described as doing a range of tasks, including running errands, doing heavy lifting, enabling transport or oral communication, and typing.

3.3.2 DIFFERING LEADERSHIP SCOPE

There were differences in the degree of management responsibilities a Leader assumed as well as in the range of tasks performed by PAs. The newer the Leader, the less likely it was that that person got at least 25 PA hours per week. A number of Leaders, especially newer Leaders, felt constrained in directing their PA service, for example in choosing their PA or in scheduling times of service delivery, particularly when they shared PAs with others. The empowering dimension of being a Leader was weakened in these cases since the individual had limited control to develop their lives. As one said, ‘My PA hours are for survival’. Another middle-aged individual observed:

“I’m part of a production system where the priority is quantity not quality”.

A third Leader remarked:

“I have little input to the service and I want more”.

31 These activities can demand a lot of time and energy from the Leader, even with support from the PA.

One young Leader was philosophical:

“Given what [hours] I’ve got, I’m getting the best out of it I can”.

Some of the Leaders, particularly more recent entrants and those with fewer hours were less heavily involved in recruiting their PAs, typically sitting on the selection interview panel and engaging during the probation period. But many other Leaders outlined the various tasks they undertook, including developing a job description, advertising, short listing, interviewing and, above all, training the PA. In the words of one:

“I go after a PA myself because it’s not just about the work. Our personalities have to match”.

Leaders use different avenues to recruit their PAs, with one young person describing a method they used very successfully but which the staff member in their provider organisation seemed to resent.³²

Although most were content with their current PAs and turnover was low for most Leaders, there were numerous stories of past problems, for example where the PA was only comfortable doing certain tasks, or not following the Leader’s direction. Literacy problems and cultural differences, inflexibility regarding work times and pressure ‘to cook’ the monthly timesheet were also mentioned. A new Leader commented:

“It’s hard to get a good PA if you can’t offer lots of hours”.

Leaders sometimes resolved the HR problems themselves but almost all those interviewed appreciated having a ‘back-up’ available, which typically meant the service provider³³. A few, however, criticised the delays in the resolution process when the Leader – PA relationship breaks down, saying that for such an intimate relationship this must happen very quickly.

In the view of some Leaders employment, health and safety regulations limited their ability to direct the service effectively. They saw a persistent medical care culture in some of the ever-expanding regulations unduly limiting the Leader’s ability to manage. One long term Leader remarked that:

“The health and safety rules are designed for business not the home”

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- 32** A few young, new Leaders felt that certain provider staff members did not really understand or accept the independent living ethos.
- 33** A few Leaders were dissatisfied with the responsiveness of their provider when problems arose, but they did not appear to be afraid to complain.

Examples given to illustrate this point included rules about dispensing medicines, use of standing frames, wheelchairs accessing pavements and requiring two PAs for hoisting. A person with a disability understands and appreciates the importance of regulatory protection³⁴. At the same time, it was noted that Leaders are motivated to respect health and safety, as one explained with regard to lifting: ‘The PA’s back is my back’.³⁵

3.3.3 ASSESSMENT OF SERVICE NEEDS

The assessment process of the number of PA hours required by a Leader raised issues for a few longer term Leaders and more so for newer Leaders in relation to insufficient PA hours and the regard given to the Leader’s whole life agenda and commitment to independent living. The person who determined the service need varied, e.g. a public health nurse, a review committee, the provider, and the person who was responsible for this role was not always clear to the Leader.

Views of Leaders on Assessment of their Needs

“If I had to apply using the new [HSE] application form, I wouldn’t get as many hours as I do. That form induces a guilty feeling if you’re seeking more than personal care – like you don’t deserve support”.

“The assessment doesn’t respect my right to independent living as my partner has to do all the night-time work plus other tasks such as shopping”.

“People who live alone get more hours because the HSE can’t shift the burden onto family members”.

“I now need more hours [due to worsening condition] but I don’t trust my provider to appreciate my needs. They are stuck in the medical model of care”.

“It’s hard to get hours to support me in raising my kids. Unless it’s a welfare issue the HSE doesn’t want to know”.

34 For example a risk assessment of their home is a regular event, with the findings implemented by the Leader in their capacity as managers.

35 Two Leaders were concerned that the rules did not enable them to demonstrate adequately their appreciation of the PA for being flexible about times and tasks.

“I had to fight the medical authorities [after acquiring a disability] to live [alone] in my own home”.

“I was urged to shop on the internet to reduce PA time enabling me to get out”.

“My request for additional PA hours [for ‘social’ purposes] was denied recently. I was told there were higher priority needs, namely, out of hospital, a change in personal care needs or in informal supports. Quality of life was at the bottom”.

“My needs haven’t been reassessed in recent years since the provider has nothing to offer.”

3.3.4 SUPPORTING LEADERS

Although Leaders were confident about handling their responsibilities, many said that learning the role wasn’t easy. For the most part they felt that they had learned ‘on the job’ and surmounted the challenges quite well. A young Leader remarked:

“You have to know how the system works – for your own sake”.

Another more recent entrant said:

“I learned from living in another country that took a can-do approach. Although I’m disabled I do everything I can, even if it’s hard. And I’m alert to assistive technology that can help me do that”.

One long term Leader admitted:

“It took a while to realise that mutual respect is critical”.

A few newer Leaders said that they were learning to act as Leaders, and to insist on good service from their PA.

The interviews suggested that information about the service – what to expect from it, how to get it and how to use it – wasn’t sufficiently accessible. One new Leader pointed out that although they had been in rehabilitation, they were ill-informed about the possibilities for a funded PA service.

The majority referred to Leader training as important. The long term Leaders had participated in intensive, consultative training while the recent entrants at the Irish Wheelchair Association had enjoyed a short training course together. Some others pointed out that they gained relevant experience prior to having PAs; for example, in mainstream education, employment or in foreign countries. However, for a considerable number it was a case of learning as they went along.

Leadership training was needed in the view of a number of interviewees, both to enable the person to take charge of their service and to support a sense of collective advocacy and understanding of the independent living aspects of the service. Concern was expressed that the more recent preparation for leadership was too focused on administration with insufficient attention to the opportunities for developing independent living. One person observed:

“I see people who are afraid to press issues [about their PA service] on their own”.

A long term Leader commented:

“We need collective action to prevent a slide away from the independent living ethos”.

As the original members were getting older, a few expressed concern about the continued vitality of the movement. Views differed on this, with one interviewee commenting:

“I worry about the young cohort of leaders picking up the fight, that they don’t appreciate the need [to promote independent living]”.

On the other hand another Leader observed:

“The young [naming some individuals] won’t put up with being shunted about”.

Amongst the pioneering Leaders, peer networking and support had developed along with their leadership training, but that was not so evident with more recent entrants. Indeed quite a few newer Leaders admitted that they had little or no engagement with their (disabled) peers. Although many were getting involved in the new Leader Fora and were participating in joint endeavours, there were also comments about the difficulty of sustaining peer engagement and activism in the disability movement.³⁶

36 Center for Independent Living supports local Leader Fora that are run by people with disabilities. A National Leader Forum is being developed as well.

As one Leader said:

“I found that there were far more followers than leaders. And campaigning took up a lot of my time plus my PA time”.

Fear about losing one's own hours (experienced by several participants), combined with the energy required simply to get on with life were considered by some to deter collective action and mutual support.

3.3.5 SUMMARY

Key points relating to leadership were:

- Managing a PA service can be time consuming and complex. Concerns highlighted included help in learning to be a good Leader, and peer support when problems arise.
- The relationship between the Leader and the PA is highly individual in character.
- Most Leaders like the degree of control they have but many newer Leaders are frustrated by their limited ability to direct their service. The uncertainty they face about future provision compromises their ability to build independent lives.
- For newer Leaders and those requiring more hours (for example due to a worsening condition) assessment of need is an issue. Criticisms made included the expectation that family members in the same household would undertake heavy care duties and the low priority given to so-called social activities.
- Although a shortage of PA hours is an issue for relatively few long term Leaders, they are concerned that Leaders need to be well prepared and supported, especially through the disability movement. They realise that their impetus to work and learn collectively, stemming from their experience of institutionalisation, doesn't apply so strongly to younger Leaders who grew up in a more mainstream environment. Most younger and more recent Leaders are ready to participate in joint action but their experience of collective engagement typically is less embedded than that of their senior counterparts.
- Greater consultation with Leaders in developing health and safety regulations would help to protect their entitlement to independent living.



**“It took a while to
realise that mutual
respect is critical”**

3.4 Conclusion

The perspectives of Leaders underlined both the value of the service in responding to highly individual requirements but also its vulnerability to constraints and restrictions that undermine its effectiveness. A number of key themes emerged from the interviews:

- a** Leaders are typically busy developing their lives in their individual ways, thereby benefiting themselves and others.
- b** The Leaders are well aware of the difference between a care and a PA service, most having experience of the former. But there are differences amongst them relating to their ability to take on management responsibility. A combination of appreciation of their service and frustration about using it was most evident for those who obtained a PA service after 2003.
- c** Sustaining and strengthening the PA service means recognising its role in supporting independent living by very diverse individuals.



Chapter 4:

Perspectives of Leaders: Future of the PA Service

4.1 Introduction

This chapter explores the perspectives of Leaders on government policy, distinguishing features of a PA service, access, quality issues, level of management responsibility, independent living ethos, and the future of the PA service.

4.2 Government Policy

Unsurprisingly, concern about government's commitment to the service is evident in most interviews³⁷. One Leader who lives in a rural area reported that they would have to give up driving soon, and: 'I can't see how I'll manage then'. Another said,

"There is fear and apprehension about the future, especially amongst parents".

According to one individual who had been a Leader for more than five years:

"I wasn't included in the decision to cut my hours – just got a letter in the post".

Another stated:

"The provider has become more restrictive, creating uncertainty for me".

A long-time Leader felt that the government underestimated the contribution Leaders made to progressing inclusion for people with disabilities in Ireland.

All the Leaders stressed the importance of the HSE respecting the differences between a care service and a PA service. They identified the features that distinguish a PA service as follows:

37 Apprehension about the future can be expected amongst individuals whose condition is largely beyond their control and who depend heavily on social services.

Box 4.2:

Distinguishing Features of a PA Service

- a. Leaders' needs are assessed against their legitimate expectation of independent living.
- b. Leaders choose their PAs, with the depth of involvement in recruitment decided by them.
- c. In selecting PAs, Leaders have access to people who respect the independent living ethos and are able and willing to work in this way.
- d. Leaders decide on the tasks and times of PA service to meet their specific needs.
- e. The Leader's capacity to manage and their right to privacy are respected.
- f. Leaders have choices about the organisation of their PA service, including the option of direct payment.
- g. Leaders get the preparation and support to fulfil their responsibilities well.

4.3 Access to a PA Service

An important theme that emerged in the discussions with Leaders was their access to a PA service. The Leaders' views did not reveal unreasonable expectations in this regard. One person volunteered:

“I’m ok but I realise for potential entrants the situation is different”.

Indeed several young people appeared to tailor their expectations around their knowledge of the significant unmet need for PAs amongst friends and others. An older Leader suggested that the government was concerned about the extra costs incurred due to the service. The Leader commented:

“Having a PA service means people become happier so that they live longer, and require the service for a longer time”.

The ways in which the Leaders accessed a PA service varied. A considerable number were involved in the INCARE pilot in the early 1990s or initiatives taken shortly thereafter. The newest Leaders typically had graduated from a purely care service while most of those in between had different stories to tell. Two outlined their struggles in getting supports after they had finished university and their educational supports were terminated. The lack of a streamlined transition from education to work was flagged as a significant barrier to independent living, especially given the low levels of education and employment participation by people with significant disabilities.

As already mentioned, a number of interviewees were concerned about the nature of the needs assessment used, in terms of respecting the whole life of the person and their wish not to over-burden family members.

4.4 Quality Issues

With regard to the quality of PAs, while the Leaders usually agreed with the need for basic provider-managed training of PAs, such as manual handling, most Leaders did not regard FETAC level 5 as ideal preparation³⁸. The subject matter did not suit some needs (for example those with sensory disabilities). Also according to a number of Leaders, appreciation of what independent living means was not always taken on board by PAs. Credentials were not considered the crucial factor in getting a quality service but rather the Leader's ability to select and to train their PAs. One interviewee commented:

“In my experience the job of a PA is individual-based, and a qualification such as FETAC is a one size fits all approach that won't suffice in today's climate. Personal traits and skills are far more important than a qualification”.

Decent pay and conditions for PAs were regarded as essential for a quality service as the job usually requires the PA to be very flexible about times and tasks. So too was Leader control in recruitment. Several Leaders preferred recruiting people with no care experience. According to one interviewee:

“Quality in a PA is about their value system. No one can teach willingness to be patient, flexible and to listen”.

Many emphasised the importance of finding a good match or ‘clicking’ with the person serving as a PA. The importance of both parties recognising each other's role was also highlighted as an important aspect of quality.

Concern was expressed about the regulation of the PA service, which the HSE may require in the future. The cost of increased ‘bureaucracy’ was one issue that arose here, but so too was respect for the Leader's privacy. Since the PA service involves very intimate work with the Leader – personal, social and financial – invasion of privacy is a real concern for Leaders. For example, one person commented:

“It's not the provider's business where the PA provides support for me”.

In this regard, it was felt that the development of HIQA or HSE standards and regulations should be co-developed with Leaders enabling a sense of ‘ownership’ of the process.

38 Providers appear to be introducing the FETAC certification as a requirement when recruiting PAs.

4.5 Level of Management Responsibility

Leaders differed in how they want to use the PA service. Some seek direct payments so that they can employ their PAs, with a few already having effectively achieved that degree of control. A Leader argued:

“People need to be in control of their own funding. The direct payment system allows the individual to employ a PA specifically to meet their individual requirements. In my opinion people with disabilities have a vested interest in the success of the service, and will strive to achieve this while it may be all too easy for [provider] organisations to lose sight of the original goals³⁹”.

However, many Leaders do not want to take on full employer responsibility. One commented: “I’d rather have the devil I know”. A second commented that it was useful to have the backing of a strong organisation. The importance of Leaders having options was emphasised by most interviewees:

“Choice of provider is great if just the administration of the service [i.e. payroll and basic training] is what the tender is about. But there is great diversity amongst users, and not all want a light touch service like I do”.

“There is a risk of dreadful bureaucracy under tendering because the service is nuanced, not cut and dried”.

Some Leaders favour a change that would give them a choice of provider but others expressed doubt:

“Ireland isn’t big enough for effective competition in tendering”.

Another Leader was concerned that choice in more remote areas would be illusory.

39 A direct payments model for people using services is well established practice in many other countries although take-up can be low.

4.6 Independent Living Ethos

The interviews noted the importance of the wider environment, in addition to the PA service, for independent living by the Leaders. For example, many volunteered that they got financial help in buying an adapted vehicle or received a mobility allowance. A considerable number living in Dublin said that they used public transport. They had homes where adaptations had been made. Most of the younger leaders had been at mainstream schools. All used the internet and email, with some active in other forms of social networking. Technological aids were also important. For example, one Leader explained how her PA assisted her to use exercise equipment designed to improve physical strength. Leaders also spoke about being involved in community services, such as sports clubs, and leisure facilities. A participant in the Offaly discussion group who had earned a place on Ireland's Paralympic team pointed to the positive impact in other areas of their life as a result.

Against this positive picture, a number of areas were noted where regulatory policies undermine the independent living potential of the PA service. Leaders can feel great pressure to break the rules simply to be able to live an ordinary life, for example, by getting transport in their PA's car despite questions about the insurance cover. One interviewee noted:

“There is pressure to consider shady practices [e.g. hire people not entitled to work in Ireland] to make the money go a little further. Also the welfare rules conspire against a disabled person being able to take on part-time work. For those with full time jobs, the tax relief cap is too low to cover the extra costs imposed by significant disabilities. ... People have to work incredibly hard to live independently, and they should be encouraged, not discouraged”.

While noting welcome improvements, many interviewees saw the narrow medical model of disability persisting throughout much of Ireland, as illustrated by one Leader's comment:

“There is a large disability budget but the government bows to vested interests and the traditional approach, leaving few resources for supporting independent living”.

Another observed that individuals with significant disabilities:

“...can build independent lives given access to a range of enablers, and using those that suit them – PA service being one possible choice. Government needs to focus on ensuring the availability of supports that promote the objective, which is an independent life”.

A young mother in the Offaly focus group considered that all members of society need to see themselves as disabled or potentially disabled; she viewed disability policy as a form of social insurance protecting everyone⁴⁰.

One young Leader who visits schools to educate them about disability explained:

“I insist that teachers not coach the kids about what to ask me. I want to respond to the kids’ concerns and interests”.

She, along with most of the other Leaders, worked actively to promote acceptance of the social model of disability.

4.7 Leading to a Better Future

Key points highlighted relating to the future of the PA service included:

- There is widespread concern, and even fear, amongst the Leaders about the future of a service on which their capacity to live an independent life depends. They are very aware of others who need the service but cannot get it.
- A quality service entails Leaders choosing their PAs, albeit the extent of involvement required depends on the Leader.
- Pay and conditions are important since PAs often have to be very flexible about times and tasks, and good inter-personal skills underpin service quality.
- Newer Leaders seem most likely to experience PAs with a care rather than an independent living ethos. These Leaders attribute problems to their constrained ability to direct the service.
- There is great diversity amongst the Leaders in how they use the service. Generally Leaders want options to choose from in the operation of the service. Some want to become employers but many across the age groups rely on their provider organisation for back up.
- Most Leaders who participated in this research are very conscious of their role in promoting social inclusion, and the importance of the PA service in this mission.

40 Australia recently introduced a funded disability insurance scheme. See www.ndis.gov.au



Chapter 5:

Conclusions and Recommendations

5.1 Conclusions

The interviews demonstrated that the PA service is much valued by the Leaders, and that it supports independent living. The findings from the interviews demonstrated that the Leaders who had the PA service for longer periods could participate in society and live an independent life, choosing and having control over the various aspects of their lives, such as their living arrangements, participation in training, education, work, and in social and community activities. Their sense of well-being was enhanced, which ultimately benefited the wider community and society.

The PA service therefore facilitated longer term Leaders in particular, to realise the entitlements set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The interviews indicated that almost all Leaders could, as a result of the PA service:

“choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement” (Article 19 (a) UNCRPD).

Younger Leaders who were living with parents intended to move out in time.

Some Leaders had the:

“personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community” (Article 19 (b) UNCRPD).

In addition there were Leaders who enjoyed the entitlements of other Convention Articles, such as the right of persons with disabilities to education. The PA service is, albeit imperfectly, underpinning Ireland’s compliance with the UNCRPD.

The Leaders are clear about what the PA service should be, as outlined under section 4.2 in the previous chapter. Core PA service characteristics include:

- 1 Leaders’ needs are assessed against their legitimate expectation of independent living.
- 2 Leaders choose their PAs, with the depth of their involvement in recruitment decided by them.
- 3 In selecting PAs, Leaders have access to people who respect the independent living ethos and are able and willing to work in that way.

- 4 Leaders decide on the tasks and times of PA service to meet their specific needs.
- 5 The Leaders' capacity to manage and their right to privacy are respected.
- 6 Leaders have choices about the structure of a PA service, including the option of direct payment.
- 7 Leaders get the preparation and support to fulfil their responsibilities.

They regard the service as a means of empowering people to engage in life, despite their physical and sensory impairments and an environment replete with barriers to participation, just as the pioneers of INCARE had intended. Yet the interviews also indicate that this definition of the PA service is being eroded. A significant number of interviewees who were quite recent entrants to the service have not been given sufficient PA hours and / or the flexibility to direct their service and build an independent life for themselves⁴¹. Their ability to use the service does not compare to that of the longer-term Leaders.

Neither the HSE documentation nor the input from providers and advocates contradicts this conclusion. In particular while the HSE definition of the PA service at first glance appears to endorse the independent living objective, on closer inspection it is ambiguous⁴². For example, when does reliance on family support significantly undermine independence? How much support for engagement in society is implied by independent living? The struggle to distinguish a care and a PA service is far from over.

In conclusion, this research, based on thirty interviews with people who have a PA service, a reading of public policy documents, and discussions with several practitioners and other stakeholders reveals the vulnerabilities of the Irish PA service. The PA service is not a care service; indeed it is more than a service per se because of the control held by the user that enables independent living. Any understanding as well as practice that ignore the larger purpose of the PA service miss the mark, and is likely to lead to counterproductive practices. The need for a shared understanding and vision for the PA service going forward is crucial.

41 There were more people interviewed with a lower degree of physical and sensory impairment amongst those who entered at or near the start of the service in the 1990s compared with the later entrants interviewed. It is also possible that more recent entrants got more supplementary home support care service than did the long-time Leaders. However these differences are unlikely to explain much of the significantly reduced PA hours typically provided to more recent entrants' vis-à-vis those who had been getting the service for more than ten years.

42 Definitions for the PA service and Home Supports as set out in the HSE's KPI Metadata 2013 Disability Services.

5.2 Recommendations

This research leads to recommendations for the consideration of government and those in the disability sector.

RECOGNITION FOR PA SERVICE

- 1 Many longer-term Leaders are apprehensive about the service continuing to support independent living for people with significant disabilities while more recent entrants often worry about their own service being sufficient for building a life. The Department of Health should lead in further developing the definition of the PA service so that it encompasses equality-based independent living, as reflected in the UNCRPD. In other words, a service should enable people with significant disabilities to pursue opportunities that the rest of the population takes for granted.
- 2 In keeping with Article 19 of the UNCRPD the Department of Justice should examine the case for establishing the PA service on a statutory basis as one of the supports enabling disabled people to participate as full citizens⁴³.
- 3 The feedback from Leaders underlines the importance of the PA service in supporting independent living and enabling people to contribute to Irish society. The Department of Health should commission an independent, holistic evaluation of the service, including social as well as economic costs and benefits.
- 4 The uncertainty experienced by Leaders is exacerbated by the lack of a designated funding stream. Since the PA service is exceptional in how it facilitates social inclusion, the government, especially the Department of Public Expenditure and Reform should explore new ways of funding the service. A national disability insurance scheme similar to that introduced in Australia could ensure secure funding⁴⁴. Another possibility is the establishment of an 'Independent Living Fund'.

43 This examination might include a review of how other Western states with relevant legislation have fared during the current recession as well as considering Center for Independent Living's Personal Assistance Bill.

44 The Australian scheme is being rolled out gradually with \$19.3 billion (Australian) to be spent by the national government over seven years. See www.ndis.gov.au.

PA SERVICE PRACTICE

- 1 The HSE urgently needs to engage with Leaders and others in the disability sector to clarify what constitutes a PA service and to put the agreed definition into practice. Pathways to direct payments, where a Leader can become the employer, also need to be developed, based on learning from international as well as Irish experience.
- 2 The PA service is currently situated in the HSE although its scope extends far beyond health care. The HSE's move to standardise needs assessment must not be simply a medical test. Having a life is much more than being able to get out of bed and equal opportunity is not just about basic care needs. The HSE's assessment process must incorporate the independent living activities named by the applicant. The association of independent living with improved well being and happiness is well accepted as relevant to our public health goals.
- 3 The heterogeneity amongst Leaders, the specificity of their use and management of the service and their ambitions for independent living is a key finding from the research. Leaders should have options about how they use the PA service, regarding the extent of responsibility they take on and on the needs they have for the service. Any HSE commissioning / tendering process must focus on each person achieving independent living, not just on general aspects of service provision.
- 4 Leaders should have the opportunity to increase their independence by taking on more responsibilities in managing their PA service. This however, depends on the quality of the support infrastructure which has mainly been provided by peer networks and organisations. With the ageing of the pioneer Leader cohort, Disability Organisations need to be innovative in engaging with people and supporting their networks. The HSE also has a role in supporting voluntary self-help. For example, information about the PA service needs to be improved.
- 5 Employment, health and safety regulations need to respect a person's right to independent living. The interviews identified several areas, including use of aids and handling of medication, where the Leader's competence was sometimes ignored. A person with a disability understands and appreciates the importance of regulatory protection⁴⁵. The development of any HSE and HIQA standards and regulations for the service should be co-developed with Leaders so that they can influence and have a sense of 'ownership' in this process. Changes to employment regulations should be explicitly evaluated in the context of home-based work.

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- 45 For example a risk assessment of their home is a regular event, with the findings implemented by the Leader in their capacity as managers.

JOINED-UP WORKING

- 1** The PA service operates in a wider environment and government needs to consider the often unintended impact on independent living of other policy provisions, such as the means-tested access to a medical card for some people with disabilities and tax credits that do not reflect the true cost of employing PAs privately. In reforming the Rural Transport Scheme ways of making it easier for mobility-impaired people to travel need to be considered. More broadly, a rigorous evaluation of the likely impact of any proposed policy changes on the UNCRPD's Article 19 commitments is essential and must be evidenced in the Government's National Disability Strategy Implementation Plan.
- 2** In a similar vein, the research revealed the importance of cross-agency co-ordination if people with disabilities are to enjoy equal opportunities. For example, people leaving education and losing as a consequence their education-related personal supports should be able to count on getting a PA service to support their subsequent careers. A home (appropriate housing) is the foundation for building a life but there are access barriers to appropriate housing and associated personal supports. A number of the younger Leaders interviewed plan in time to leave their parental home, an ambition that would be hard to realise at present. The co-ordination achieved to date under the National Disability Strategy (NDS) has been disappointing; performance by government departments and agencies needs to markedly improve.

DEVELOPMENT OF THE PA SERVICE

- 1** It is uncertain whether monitoring under the NDS Implementation Plan will adequately evaluate policy and practice with regard to the PA service. Given the rapid pace of change in the area of policy on personal supports and independent living, it makes sense for the Disability Federation of Ireland or another voluntary disability organisation to repeat this review of Leader experience a few years hence.



Appendices

Appendix 1: The Leader Interviews

The vast majority of the one-to-one interviews (23) were held face-to-face, mostly in a neutral location but occasionally in the Leader's home or an office. Where the Leader chose, a PA to assist with communication was also present at the interview. Participants' confidentiality was assured. Each session lasted approximately one hour. The interviews took place between late May and early August, 2013.

The disabilities of the interviewees were varied, with deafness the one obvious condition not encountered. Twenty six used a wheelchair. Numerous participants had a disability from birth; for others their disability either emerged or was acquired after childhood. Some volunteered that they had additional disabling long term conditions. Few said that they did not require assistance for their basic personal care. In those cases assistance in running the home, in outside activities and in transport were tasks assigned to the PA.

Some Leaders were receiving a FÁS – funded PA service and a significant number also got a HSE-funded care service. There were eight leaders with 5 years or less of funded PA service; seven with 6 to 10 years of service; six Leaders with 11 to 18 years of service and nine with 19 or more years of service. Those not using a wheelchair were evenly divided between the two shortest periods for PA service. Amongst the seven younger (aged under 35) Leaders, three had received a PA service for five years or less while the rest had the service for ten years or less. There were also cases of older Leaders having the service for relatively short periods.

There was also a positive relationship between those who were receiving the service for longer and the number of hours of PA service they received. For Leaders with five years or less of service, 25% got at least 25 hours per week, compared to 43% of Leaders with 6 to 10 years' service and 50% of those with 11 to 18 years of PA service. Amongst Leaders with at least 19 years of service, 90% got at least 25 hours. Having said that, there were individuals within each of the groups who received a lot more hours and others who received a lot less, suggesting that degree of the disability, availability of family support and other factors played a role along with length of time person was in receipt of the service.

INTERVIEW SCHEDULE WITH PEOPLE USING A PA SERVICE

A FACTS:

1. Your PA service Provider(s)?
2. Current hours of service / week PA vs HS?
3. Number of PAs during the week?
4. PA duties (e.g. basic life supports, driving, communicating etc)?
5. PA turnover – is this a problem?
6. Living situation (e.g. own apartment? Sharing with partner or other?)?
7. Transport situation (e.g. own car)?
8. Do you use the internet?

B USE OF A SELF DIRECTED PA SERVICE

When first received service? [Why were you seeking it?]

1. What training did you receive? Was the training satisfactory?
2. What about peer support?
3. What did you want to use the PA service for? What were your plans?
4. How did that go?

Recent experience with the service

1. Security of supply over previous two years; changes in continuity of service; flexibility e.g. on scheduling time
2. Any resort to privately funded service?

C KEY EMPOWERING FEATURES:

Does the ability to manage the hours of PA time matter to you?

Your experience in using PA service to support living independently:

1. Is your input to the assessment of your need for the PA service respected? Was advocacy support available?

2. Is there a risk assessment done, and are you able to take reasonable risks to achieve greater independence?
3. Experience in getting service to suit, in terms of recruiting PAs, negotiating with provider for scheduling hours and tasks; supporting and training PAs, addressing HR issues?
4. Would you like to have more control, and responsibility regarding your PAs, given adequate training and support? Would you like Direct Payments?
5. Has peer support and networking been important for getting the most out of the service?
6. Do you feel confident about managing your service and your PAs?

D OUTCOMES:

The difference the service makes to your life and also to wider society:

1. How service enables independence / self determination (E.g. energising effect of having a support under one's own direction)
 - a. Enabling to live in own home and support family.
 - b. Enabling social participation – activities person enabled to do and contributions made to the movement and to wider society.
 - c. Enabling study, part-time or full-time employment
2. Impact on others, e.g. family members.
3. Any negative consequences due to using PA service?

E GOVERNMENT (AND HSE) PLANS TO CHANGE PA SERVICE ARRANGEMENTS

- Can you describe key features of the PA service that must be respected if changes are introduced? What are critical for choice and personal control over the service?
- How can the quality of the service be assured? In particular is a requirement of FETAC Level 5 for PA applicants appropriate / sufficient? What about PA pay and conditions?
- Is Leader privacy a concern, especially given the HSE's attention to 'accountability'?

F INFLUENCING GOVERNMENT POLICY ON PA SERVICE

- How can people with disabilities influence government policy regarding PA service?
- Are there activities you undertake to influence government in this regard?

Appendix 2: PA Service and the Independent Living Movement

The genesis of Ireland's PA service – emanating from active research and lobbying by individuals with significant physical and sensory disabilities – makes understanding the perspective of the pioneers critical to any policy discussion. Those pioneers not only founded a new approach to services but they also gave impetus to a disability movement. There is a considerable body of literature about the inception of PA service in Ireland that is listed in the bibliography.

As members of the disability movement see it, the Personal Assistant service contributes to realising human and civil rights, and the expectation of equality of opportunity for all members of society. PA service is an integral component of equality by facilitating independent living. It helps to level the playing field for those with significant impairments and promotes a move towards a more 'disability friendly' environment and social culture, without access barriers and attitudinal constraints.

With the service a person with disabilities manages the specific personal supports so that they can participate and have a life, just as non-disabled people do. The person using the service knows best what their needs are and the support their personal plans require to be achieved. PA service puts the user in charge of their service delivery; they become a Leader⁴⁶. Control and management of the service turns the recipient from being an object of 'care' to instead being the director of their personal supports.

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46 According to an international pioneer of independent living, Adolf Ratzka, "...Personal assistance means that users exercise the maximum control over how services are organised and custom-design their services according to their individual needs, capabilities, life circumstances and aspirations. In particular, personal assistance requires that the individual user decides:

- who is to work,
- with which tasks,
- at which times,
- where and how.

Thus, the individual user must be able to recruit, train, schedule, supervise, and, if necessary, fire his or her own assistants. Simply put, "personal assistance" means that the user is the boss...." www.independentliving.org/docs3/stileng.html

The Leader chooses how to use the service to support him / her to lead a meaningful life. When the work includes assisting basic and intimate life functions of the Leader, managing the service really is taking charge of their person. It is liberating for them. At the same time this Leader role is demanding, requiring discipline, confidence, knowledge and skills. A PA service obliges the user to take significant responsibility in managing their PAs; at the highest level they are the employer.

Leaders should be supported in fulfilling their role through peer networking and training. This involves sharing expertise and experience with peers, joint problem solving and helping one another⁴⁷. This networking also enables Leaders to advocate most effectively in favour of the social model and policies to underpin independent living for all in the wider community.

The movement has influenced the development of disability policy in Ireland over recent decades. The pioneers of the service in Ireland and elsewhere prompted a radical revision of what disability means, away from disability caused by individual medical failure to it being the result of society's failure to act to include every citizen. They advocated the right to independent living, to having choice and opportunities as do other members of society⁴⁸. One outcome is the UN Convention on the Rights of Persons with Disabilities, which Ireland has committed to ratify.

47 The Leader needs to keep abreast of technological developments and other changes, including changes in their disabling condition that may affect their PA service needs, for example.

48 For further information about independent living, see www.dublincil.org and www.enil.eu/policy.

Appendix 3: National Statistics on Personal Assistant and Home Support Services

NATIONAL PHYSICAL AND SENSORY DISABILITY DATABASE

	PERSONAL ASSISTANT	HOME HELP	HOME CARE ASSISTANT
SUPPLY			
Number using in 2012	650	650	650
DEMAND			
Unmet need	1308	1685	646
Enhanced / alternative service	260	650	96
Overall demand	1568	1924	742

Health Research Board, Annual Report on the NPSDD Committee, 2012, Tables 3.3 & 3.4. Note that the Database is voluntary and the count only covered the 6,897 persons who had registered or been reviewed during the previous year. *Of the 650 PA service users, 535 were aged 18-65 years, the remainder being younger.

HSE NATIONAL OPERATIONAL PLAN 2013: IMPLEMENTING THE NEW SERVICE PLAN 2013⁴⁹

TOTAL FOR ADULTS AND CHILDREN WITH PHYSICAL AND / OR SENSORY DISABILITY BENEFITING FROM HOME SUPPORT HOURS (INCLUDING PA)*		
	NUMBER OF PERSONS	NUMBER OF HOURS DELIVERED
Target 2012	4038	1.68m
Target 2013	4166	1.68m
TOTAL FOR ADULTS WITH A PHYSICAL AND / OR SENSORY DISABILITY BENEFITING FROM PA HOURS		
Target 2013	New subset	New subset
TOTAL FOR ADULTS AND CHILDREN WITH A PHYSICAL AND / OR SENSORY DISABILITY BENEFITING FROM HOME SUPPORT HOURS		
Target 2013	New subset	New subset

49 Note that the data is to be broken into subgroups of users in the year-end 2013 report.

Appendix 4: List of Acronyms

ANED – Academic Network of European Disability

ÁT – Áiseanna Tachaíochta

CE – Community Employment

CIL – Center for Independent Living

DFI – Disability Federation of Ireland

DoH – Department of Health

ENIL – European Network of Independent Living

EU – European Union

FÁS – Foras Áiseanna Saothair

FETAC – Further Education and Training Awards Council

HIQA – Health Information and Quality Authority

HR – Human Resources

HS – Home Support

HSE – Health Service Executive

IWA – Irish Wheelchair Association

KPI – Key Performance Indicator

NAS – National Advocacy Service

NESC – National Economic and Social Council

NDS – National Disability Strategy

NPSDD – National Physical and Sensory Disability Database

PA – Personal Assistant

T.D – Teachta Dála

UK – United Kingdom

UNCRPD – United Nations Convention on the Rights of People with Disabilities

UN – United Nations



**“personal assistance
necessary to support
living and inclusion
in the community”**



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Notes

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The **Disability Federation of Ireland** (DFI) represents the interests and the expectations of people with disabilities to be fully included in Irish society. It comprises organisations that represent and support people with disabilities and disabling conditions.

The vision of DFI is that Irish society is fully inclusive of people with disabilities and disabling conditions so that they can exercise their full civil, economic, social, and human rights and are enabled to reach their full potential in life. DFI's mission is to act as an advocate for the full and equal inclusion of people with disabilities and disabling conditions in all aspects of their lives.

There are over 126 organisations within membership, or as associates, of DFI. DFI also works with a growing number of organisations and groups around the country that have a significant disability interest, mainly from the statutory and voluntary sectors. DFI provides information, training and support, networking, advocacy and representation, research and policy development / implementation, and organisation and management development.

DFI works on the basis that disability is a societal issue and so works with Government, and across the social and economic strands and interests of society.



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