

Center for Independent Living Leader Forum Consultation
Report: Personal Assistance Services.

Dedicated to Martin Naughton
1954 - 2016

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Executive Summary

This report details the views of people with disabilities on the theme of Personal Assistance Services (PAS) based on consultations held over a two-year period.

The Center for Independent Living (CIL), on behalf of Leaders nationwide, calls for legislative protection for personal assistance services and the ring-fencing of funding for personal assistance services within the wider HSE budget. There is a need to increase supports to small organisations to deliver personal assistance services regionally and to increase the PAS budget to allow more people with disabilities to avail of PAS. A huge number, over 1,600 people, remain on waiting lists for services nationwide. For many this means remaining in costly residential settings.

There is a need to address the waiting lists for personal assistance services, simplify the application process and generate awareness of the value for money of personal assistance services.

During a period when we see the restoration of pay that was cut following the economic collapse for those in employment, a corresponding reversal and, indeed, further additional investment should be made in services that enable people with disabilities to participate in society. The State should approach the provision of such services from a human rights perspective.

Section 1: Introduction

1.1 Introduction

The purpose of this report is to gather the learning, experience and knowledge of members of the Center for Independent Living on the theme of personal assistance services and to use that intelligence to make recommendations to the various stakeholders based on the lived experience of disability and the lived experiences of those who are actively using personal assistance services through an assortment of service providers nationwide. This report will be used as a tool for both the Center for Independent Living as an organisation and for members to advocate for a Personal Assistance Service Bill, the right to personal assistance supports and standards and quality of services.

1.2 The Center for Independent Living

The Center for Independent Living (CIL) was established in 1992 as a user-led organisation and is committed to the recognition of people with disabilities as equal citizens and to their achieving equal membership of society. This includes the ability to make informed decisions about our own lives in accordance with individual needs and lifestyle choices, to design and develop our own services and to achieve equality of experience through consensus, respect and the valuing of all.

The Center for Independent Living is the national representative and advocacy voice of the independent living philosophy around the country and it strives to ensure that the voice of people with a disability is listened to at policymaking and service provision levels.

The Center for Independent Living established the first personal assistance services in Ireland and since then has advocated for high-quality services based on the philosophy of independent living and the values of choice, control and empowerment. The guiding principles of CIL include:

- To work from the bottom up, as a grassroots organisation led by people with disabilities, to ensure that decision making within the organisation is led by people with disabilities;
- To work from a rights-based approach based on the principles of community development, in particular equality, capacity building, empowerment, awareness raising, inclusion, collective action and social justice;
- To deliver peer-designed and peer-led supports and services in a timely, efficient and person-centred way;
- To deliver comprehensive, independent services with professionalism and expertise from a person-centred approach;
- To listen to Leaders and respect their individual needs;
- To provide services and supports and to implement change in relation to social, economic, political and environmental developments;
- To work in partnership and collaboration with others in order to share expertise, access mainstream services and avoid duplication;

- To interact with the community with openness and integrity;
- To approach all work with respect for the autonomy and the diversity of the network of CILs;
- To operate in an accessible manner and to ensure that all events, projects and resources are designed and delivered with accessibility at their core.

1.3 Personal Assistance Service

Personal assistance is the necessary assistance required by a person with a disability to ensure that he or she can participate as a full and equal member of society.

Personal assistance is directed by the person with a disability and responds to the needs of the individual as they arise, inside and outside of the home, throughout the person's life. The purpose of personal assistance is to ensure that people with disabilities enjoy the same opportunities as all members of society, that they have the same choices as others and to give them the means to control how they wish to pursue their lives.

Personal assistance is applicable to aspects of personal care, domestic duties, family life and inclusion in society and in places of work, education and training.

1.4 The Leader Forum

A Leader Forum is a collective of people with disabilities who share common goals and experiences and who come together to examine how policies, services and provision might be organised to best meet the needs of people with a disability.

The purpose of the Leader Forum is to offer Leaders, members of CIL, the opportunity to come together to share peer support and to advocate for equality and social justice based on the lived experience of disability. Leader Forum groups meet both on a county basis and at national level to address inequality and to promote the social inclusion of people with disabilities. The Leader Forum acts as a space to empower the voices of members and to provide a unified voice for Leaders.

1.5 Leader Forum Consultation Process

Leader Forum members are offered an opportunity each month to inform research and CIL policy and to direct what issues should be prioritized for research. In the consultation, they are asked a series of questions each month on a priority topic. Their feedback is collated into a report, which CIL uses when representing the Leader Forum at national level. This report will be available to all Leader Forum members and Leader Forum members will be updated on progress made and on actions taken by the Center for Independent Living on the concerns and issues raised. Support and recommendations for action at local level are made also.

1.6 Consultation on Personal Assistance Services

Leaders were consulted on the issue of personal assistance services over a two-year period starting in 2013. The first consultation took place through a national consultation event held in Dublin that specifically dealt with the need for legislation to support personal assistance

services. Members were invited to discuss a draft Bill and to offer their views and recommendations on the content.

The second phase of consultation focused on service delivery and involved circulating a list of questions to all Leader Forum groups (Appendix 2). The questions related to members' experiences of personal assistance services. Members were invited through Forum meetings around the country to contribute their ideas and views.

1.7 The Policy Context

Personal assistance services have been operating as a pilot project supported by the HSE for the past 22 years and this remains the legal basis. There is no legislation currently in place in relation to personal assistance services.

The lack of any legislative protection for PAS had long been of concern to CIL. It was working on drafting a Bill when, in August 2012, the Government, without warning, announced that it planned effectively to scrap the personal assistance budget for the rest of that year. The response to this was a protest led by the Leaders Alliance with the support of CIL, which resulted in the decision being reversed. CIL decided to prioritize the Personal Assistance Service Bill. Following this, CIL began a consultation process in 2013.

On 7 May 2014, the preamble to the Bill was adopted by Seanad Éireann in the form of a motion, which was debated for over two hours and got the support of all. Some 21 senators spoke and the motion was passed without a vote.

CIL subsequently approached all political parties and many independent TDs with the draft Bill. Meetings with several government departments and the HSE followed. The Bill was included in CIL's election manifesto and CIL continues to advocate for the development and adoption of this Bill.

Section 2: Consultation

2.1 Consultation: Phase 1

Fifty-three participants, mainly members of various CIL Leader Forums around the country, attended a national consultation day organised by the Center for Independent Living (CIL). The event took place at the F2 Centre, Rialto, and Dublin 8. The purpose of the event was to discuss a draft Personal Assistance Service Bill prepared by CIL and to gather feedback from Leaders and supporters of the independent living movement.

The morning session was chaired by Michael McCabe, chairperson of CIL. Four key speakers addressed the first session:

- i) Martin Naughton: co-founder of CIL, founder of Áiseanna Tacaíochta, director of European Network on Independent Living (ENIL) and a highly-regarded disability activist;
- ii) Owen Collumb: a director of Greater Dublin CIL who runs his own personal assistance service through a pilot programme established by Áiseanna Tacaíochta;
- iii) Marian Harkin: an MEP who was recently appointed vice-chair of the European Parliament Disability Intergroup;
- iv) Gary Lee: CEO of the Center for Independent Living.

Martin Naughton: Bringing Personal Assistance Services to Ireland

Martin Naughton discussed the founding of CIL and the development of a pilot personal assistance service based on the philosophy of independent living. Martin described a visit to Southampton CIL via London to gather information and learning from like-minded peers in the UK.

This included a reconnaissance mission to England which, at one point, involved negotiating a wide van, borrowed from the Irish Wheelchair Association, over a narrow bridge to cross to the other side. Against the odds and somewhat defying physics, they made it through. It was a fitting metaphor for the struggle to establish personal assistance services in Ireland and to have the Government continue to fund it and eventually to extend it throughout the country. A week-long volunteer personal assistance service was run as part of the funding campaign.

Martin, Michael McCabe and six others then set about securing funding from the EU for the pilot project. Martin said that, while he seemed to have got most of the credit, this really should go to many other Leaders around the country who made things happen.

Owen Collumb: Managing Personal Assistance through Direct Payments

Owen Collumb reflected on his own personal history during this time. He gave a very honest and frank account of his personal circumstances and his response to acquiring his disability.

He spoke about how he had developed during the 21 years since personal assistance was established in Ireland.

Owen then discussed his experience of using direct payments to manage his PAS through the Áiseanna Tacaíochta pilot project. Owen also spoke on some of the challenges facing those who wished to manage their personal assistance services through direct payments and shared the benefit of his experience.

Owen described some of the models of direct payments and the one that was chosen for the pilot. In order to receive direct payments, Owen had to set up a limited liability company and a micro-board (a circle of support) to support him. Owen recounted that, at the beginning of the process, this had involved a huge amount of paperwork, administration and red tape but now it had become natural and second nature to him. However, even with his circle of support in place and having established himself as a company and gone through all of the paperwork, payments were still not made to him directly but through a brokerage system with Áiseanna Tacaíochta. The end result, though, is that Owen has control over his own service.

Owen was particularly busy on the day. In addition to his speech, he also facilitated one of the consultation sub-groups and prepared the report for the group rapporteur.

Marian Harkin (MEP): Comparison with Direct Payments to Farmers

Marian Harkin MEP said that many farmers who received direct payments were smallholders and they got their payments for very legitimate reasons. However, she noted the point that they got paid directly whereas people with disabilities did not. She said that there was an assumption that the farmer was responsible and would be accountable but this assumption did not seem to apply when it came to direct payments to people with disabilities. She spoke of her role in the EU and the relevance of what goes on in the EU to the lives of people with disabilities in Ireland. Marian noted that the anti-discrimination Directive that had gone through the EU Parliament was now stuck at the EU Council. She discussed social cohesion funding and gave an insight into the current EU budget negotiations and the real impact that they could have on the average person with a disability in Ireland.

Gary Lee: Legislative Protection for Personal Assistance Services

Gary Lee related two news items from the morning news. The first one was about a mother of two who, although not ill, had been in Beaumont hospital for the past two years at a cost to the State of €500,000. She could live at home but she had been refused a housing adaptation grant and could not get home support. The result was her effective imprisonment in hospital whilst her children were deprived of a mother.

The second news item concerned direct payments to farmers. Some 114,000 farmers received direct payments of which the 10 largest payments, all made to food companies, ranged from €299,000 to €434,000. Over €1.5 billion was given to Irish farmers annually in this way yet, when it came to direct payments for people with disabilities, the Government refused to introduce this and talked of the difficulties that would be involved and the lack of accountability.

Gary then went through the provisions of the proposed Bill in detail and some feedback that had already been received. The Bill would give a right to PAS to those who needed it and it would set up an independent appeals process. It set out what PAS were and who could qualify to be a PA. Gary then discussed each section of the Bill and some feedback as follows:

Section One – Purpose and Scope of the Bill and Policy

To enshrine a right to personal assistance services for all people with disabilities in Ireland, regardless of means or age.

Section Two – The Person with a Disability

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments that, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

This definition used in the Personal Assistance Service Bill is the same definition of a person with a disability that is currently in use by the UN Convention on the Rights of Persons with Disabilities (UNCRPD). This definition is used because it is the international standard and has been widely accepted as the most appropriate working definition of disability.

Section Three – The Purpose of a Personal Assistant

1. Inclusion of hours for social events, emergency hours
 - It has been suggested that, in addition to the weekly complement of hours allocated to each Leader, consideration be given to additional hours for social events and for emergency situations.
2. PA working for many Leaders
 - Our feedback has shown that Leaders prefer to have a PA working only for them. In the current economic climate, and given the resources available to PA service providers, this may not be possible. However, we suggest there should be a maximum number of Leaders for each PA.
3. Administrative control
 - Leaders have requested that they have administrative control of their PAS. Although this may not be immediately possible, it is hoped that there will be increased inclusion of the Leader in the planning and implementation of PAS and that gradually this will increase to include the administrative elements of managing a PAS.
4. Sexual requirements and childminding
 - Leaders have requested more information on this issue and this will require an additional document and consultation to develop further guidelines.

Section Four – Eligibility for Personal Assistance

1. A person with a disability shall be eligible for personal assistance where such personal assistance is necessary to enable that person engage fully and effectively in society.

Section Five – Assessment for Personal Assistance

1. Consultation on assessment logistics.

- This issue requires the HSE to work in conjunction with Leaders when organizing their assessment services. It means that, when planning assessments, the time, date and location of the assessment will be planned with the Leader.
2. Extra hours
 - Leaders have requested that an additional bank of hours be provided for each Leader, or between a number of Leaders, for situations that occur outside of the hours of assessment, for example, appointments with doctors, job interviews, etc.

Section Six – Organisation of Personal Assistance

1. Training for Leaders
 - Training for Leaders in managing their service has been requested. Training would act to support Leaders in directing their service in an autonomous way and would serve to remove barriers to participation in PAS and direct payments services. This training should be provided by CILs.
2. Types of Direct Payment
 - Direct payment could be used to secure services from a registered provider or could be used by the Leader to directly employ a PA and cover all their employment costs. (See Appendix A)
3. Compliance with Employment Legislation
 - When designing and implementing Direct Payments, it is important to note that PAs are employed in compliance with the Employment Equality Act 1998.
4. Transferrable services
 - The transfer of services between different EU jurisdictions will require legislative change from the EU Parliament.

Section Seven – Qualifying as a Personal Assistant

Making personal assistance a profession is a long-term goal of the Independent Living Movement. It will require the long-term organisation and collaboration of Leaders and PAs to establish a National Board of Personal Assistance and third-level and professional qualifications.

1. National PA qualification
 - A national PA qualification is part of the long-term aim of CIL of turning PAS into a profession and CIL will work towards establishing a national PA qualification.
2. Need for an education minimum
 - There has been much discussion about the need, or not, for a minimum educational qualification or standard for personal assistants. Currently, this has been set at FETAC level 5 and is meant as a minimum qualification. The purpose of a minimum qualification is to ensure minimum industry standards.
3. Family
 - The issue of family members being employed as personal assistants was raised for inclusion in the PAS Bill. With regard to the broad nature of the Bill, CIL chose to include family members as being eligible to become PAs. This does not mean that Leaders are limited in their choice of PA. It also means that the Leader-PA relationship will have to be governed by a strict code of management, with allowance for third-party intervention.

Group Session

Following a break, participants split into groups for the consultation and discussion session. Each group was facilitated by a Leader; Katie Bourke, Marian Maloney Nolan and Owen Collumb. Supported by a group rapporteur, the groups discussed each section of the proposed Personal Assistance Service Bill so that amendments could be made to the Bill based on the Leaders' input. Each rapporteur reported back to the main group of participants. The amended Bill was sent out to the participants in August for further feedback.

2.2 Phase 1 Feedback on Personal Assistance Policy

The importance of the values of independent living – choice, control, options and empowerment – was emphasised. Language should be focused on ‘self-direction’, ‘self-determining’, ‘self-governing’ and not on dependency. The focus should be on empowerment of Leaders and legislating for resources to do so. The person with a disability should not be represented as passive but as an active participant in the management of their service.

2.2.1 Section 3 of Bill: The Purpose of Personal Assistance

Feedback on this section of the Bill was concerned with:

- Social Inclusion;
- The all-encompassing scope of personal assistance;
- Family rights support, which might be separated from care of children as the PA is not insured.

Recommendations

The personal assistant should be funded to undertake travel activities with the Leader and to help the Leader take part in training for sporting activities and to attend meetings. He or she should be available to help maintain all areas of the house and to provide personal care such as the administration of first aid and injections. Although the Bill includes ‘assistance with looking after children’, the nature of the PA’s responsibility to help the Leader fulfil his or her role as parent needs to be defined. Care of children might need to be excluded because the PA would not be insured. There was also a possible problem of insurance cover for the administration of the Leader’s medication – CILs do not administer medication for this reason. However, a point was made that the Bill could ensure the right to this service and therefore insurance could not be refused.

2.2.2 Section 4 of Bill: Eligibility for Personal Assistance

Leaders’ comments on this section called for legislation on eligibility to be inclusive rather than rigidly based on medical guidelines, though one comment called for strict criteria for assessment. A broader spectrum in the definition of disability would allow supports for people with dyslexia who cannot read food labels. The rights of over-65s to PAS needed to be strengthened too.

The location of the Personal Assistance Service scheme in the Department of Social Protection would help move away from a medical to a social model of services. Otherwise there is a risk that service provision would be affected by risk management on the part of the HSE. The choice of language was important to avoid the perception that PAS were for ‘sick people’. Leaders’ circumstances differed, from strong to vulnerable positions, which influenced their need for supports. Although the role of the PA needed to be developed as a professional job, it should be clarified that this did not mean it was part of the ‘caring’ professions.

A number of points were made in relation to training. The need for legislation for accredited training was questioned in some feedback. It was pointed out that the Leader could provide on-the-job training for the PA or individual PAs could choose to do training. Other contributors envisaged the introduction of specific PA training based on principles of independent living rather than on a medical basis. There was potential to design specific accredited training modules.

Recommendations

The social welfare means test should be abolished and everyone should be entitled to PAS and transport irrespective of means. Eligibility for PAS on the grounds of mental health should be considered, although this would raise the questions of the severity of the person's condition and whether it might be temporary. If the Leader is to direct his or her services, how does a person with mental health disabilities do so? In terms of employing a PA, legislation needs to define the person with a disability as the employer.

2.2.3 Section 5 of Bill: Assessment for Personal Assistance

At present, there is no consistency in assessment of need. The use of a means test, carried out by the Department of Social Protection (DSP), opens the possibility that test criteria could be changed in every Budget, leaving the person with disabilities vulnerable to loss of services or hours.

The role of the Department of Social Protection envisaged in the Bill was questioned on the basis that the DSP had a less open culture and lacked understanding of people's needs. It would take a long time to change practice in the DSP whereas the HSE had better understanding and knowledge. Changing to the DSP might leave people worse off. CIL should consider other options or departments. This point was developed further with a suggestion of taking a cross-departmental approach, building expertise and understanding on a knowledge base, rather than restrict PAS administration to one department. This is currently the case with the Disability Act where assessment officers work across departments.

Discussion of the assessment process also dealt with the question of self-assessment of needs. The Leader must be at the core of the process for assessing needs and hours. It was important for the individual to have a say in allocating hours as they knew best how long a task would take. In this context, it was suggested that the first paragraph of this Section should include self-assessment and the third paragraph should be deleted. In Paragraph 4, the term 'person-centred planning' should be changed to 'self-assessment empowerment plans' or 'self-assessed empowerment plan'.

However, resources would be needed to support and empower Leaders to be decision makers and assess their own needs. There was a need to develop Leaders' skills to direct their services as not all Leaders were equipped to do this. This could be done through training, an advocate or other means.

Some feedback was concerned that obligatory training would take choice away from the Leader. The emphasis should be on facilitating choice in the Leader's life and helping them

direct their lives and not on training them to be human resources experts. Training for PAs did not need to be task-specific as Leaders could give direction although the point was made that not all Leaders were strong enough to do that. Concern was expressed over possible discrimination against PAs with literacy issues.

Feedback showed agreement for the definition of the Assessor/Assessing Officer and their independence of the funding department. Suitable training to qualify the Assessing Officer for their role was raised.

Recommendations

In paragraph 3, dealing with the maximum period for deciding on an application, change the words 'three months' to 'two months'. The allocation of PAS should be based not on hours but on needs and references to hours in the Bill should be deleted. Assessments should cover social needs and also irregular hours or occasional but recurring needs, such as visits to the bank.

The feedback had discussed different training options but there was overall agreement that the PA should be trained in advance and CIL should design and deliver training programmes but with flexibility to address differing individual needs.

Assessment Officers and other personnel involved in management of PAS must have a good knowledge of disability and equality principles and this should be covered in their mandatory training.

Records for PAS should be kept.

2.2.4 Section 6 of Bill: Organisation of Personal Assistance

Paragraph 2 of the Bill sets out four optional mechanisms whereby a person can receive their assistance. Feedback urged that a Leader should have the choice of using any of these options, a combination of them or none but that the focus should be on the decision being made by the person. To emphasise this, terms such as 'self-direction', 'self-determining', 'self-governing' should be used in this and in all sections. There was a concern that choice might be taken away from the Leader and it was emphasised that the Leader had to control who and how the PAS were delivered. Services needed to be easy to use and able to be customized to the person's needs.

A direct payment system might or might not require the person with a disability to set up a company depending on whether the payment was used to procure services from a registered provider, who would do the payroll and administration, or to employ a PA directly. All agreements on services, from the department or between the Leader and a service provider or PA, should be confidential.

Recommendations

This section should include the option of a multi-departmental approach to the administration of PAS.

The second part of Section 6 should be re-written to include language focused on self-determination and emphasis on control being in the hands of the Leader. In paragraph 3 of the second section, referring to the various organisational structures that a registered provider might take, 'trustees' should be included along with micro-boards.

The Bill should make provision for the inclusion of the Leader in the tender process for services. It should set out clear standards that service providers should meet and should require the monitoring of all service providers to ensure they meet minimum standards.

In the second part of this section, make reference to the need of the service provider or Leader who directly employs a PA to comply with employment law. It should require that PAs who provide services be paid according to standard rates.

2.2.5 Section 7 of Bill: Qualifying as a Personal Assistant

Discussion on this section dealt with who could work as a personal assistant, who should decide and the pros and cons of a person's family taking the role of personal assistant. While various contributors felt that a family member acting as PA could blur lines and expose the Leader to pressure or abuse, it might also be beneficial in terms of trust. A person who was related but not part of the immediate family might be suitable. However, family might be the only source of support a person with disabilities might have. If family members act as PAs, the situation would need to be monitored. Swedish legislation includes a third-party clause.

The issue of emergency or respite care was raised. Again, it is the choice of the Leader but when a family member gives emergency or respite cover, they should be paid for it.

Always, the emphasis needs to be on the Leader having the power to decide who their PA should be. There would always be a need to recognize unique conditions and that exceptional circumstances might require unique solutions.

Recommendations

In the first sentence, replace the reference to FETAC Level 5 with the point that training should be defined by the Leader. In section (a) of the first sentence, the leader should decide who the PA is and also who should provide emergency respite. When a family member acts as PA or gives emergency respite, they should be paid.

The section listing categories of hours should be extended to include emergency cover. More clarity is needed in the section on wages.

2.2.6 Issues to be followed up

- Every Center for Independent Living should have a peer support officer to organize for or provide support for Leaders.
- The question of which is the most appropriate government department to administer PAS, whether Social Protection or Health, needs to be decided.

- Consideration is needed about including PAS for the over-65s in legislation. Although this should be the case, there might be a risk that the potential cost of extending the service would alienate the Government and might give a rationale for cutting or removing existing PAS in the long term.
- In Section 5 of the Bill, change the appeal period from 14 days to 30 days.
- CIL needs to decide whether the phrase 'person-centered planning' should be changed to 'self-assessment empowerment plans' or whether it would be better to stay with the language currently in use by the HSE in terms of service delivery.
- A decision is needed on whether to seek to have PAS allocated in terms of need or hours. In theory it should be based on need but CIL has to decide whether it is better to stay with hours since, from the HSE's point of view, hours are easier to quantify and are more neutral than need.
- Work towards achieving a situation where Leaders can manage their own PA service.
- Make provision for emergency and occasional hours in the Bill and in existing services.
- Address the need to have services transferrable across the EU, including possible legislation.
- Work towards preparation and delivery of training supports.
- Employment.
- Housing.

2.3 What happened between Phases 1 and 2?

2.3.1 Overview

Leaders throughout the country were asked to make contact with members of Seanad Éireann to raise awareness of the key issues discussed in the first phase of consultation.

Following a two-hour debate in the Seanad, the motion below was passed by the Seanad on 7 May 2014. A huge ‘thank you’ is due to all the people across the country who contacted their local senators.

2.3.2 Seanad Motion

That Seanad Éireann:

- Notes that Article 19 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) provides that States should recognize ‘the equal right of all persons with disabilities to live in the community, with choices equal to others’ and commits States to ‘take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community’;
- Notes the commitment in the Programme for Government 2011 to ensuring ‘that the quality of life of people with disabilities is enhanced’ and further that the Government will ‘facilitate people with disabilities in achieving a greater level of participation in employment, training and education’;
- Notes that the aim of the National Disability Strategy is to support equal participation in society for people with disabilities;
- Notes further that the provision of Personal Assistance Services can facilitate the full participation of people with disabilities in society;
- Acknowledges the progress made by the Government in respect of the Programme for Government commitments on facilitating the full participation of people with disabilities in society, particularly in:
 - the publication of the Value for Money and Policy Review of the Disability Services, which will lay the foundations for a new system of individualised budgeting, which will allow people to exercise greater choice and control, enabling them to live fully inclusive, active and independent lives within the community;
 - the publication of an implementation plan for the National Disability Strategy;
 - the development of a comprehensive employment strategy for people with disabilities, which will be published this year as set out in the Action Plan for Jobs 2014;
- Calls on the Government to support the provision of a ‘Personal Assistance Service’ within the overall framework of the migration to a person-centred supports model, in order to provide people with disabilities with the necessary assistance to live and engage independently as members of society in equal measure to their non-disabled peers.

2.4 Consultation Phase 2 Service Delivery

2.4.1 Consultation Purpose and Process

Between May and December 2015, the Center for Independent Living opened a second phase of consultation. Consultation was facilitated by two methods and Leaders were invited to make their contribution to the consultation either by participating in focus group discussions through the Leader Forum or by replying to an online survey.

Discussion was prompted by a series of questions (Appendix 2) and the responses made through both methods dealt with many aspects of working with personal assistance services that the respondents had experienced. Many contributors touched on a number of points. In the following sections, all individual comments dealing with a similar issue or theme, such as the ability to participate in society or education, have been collated.

2.4.2 Feedback

Question 1: Why are Personal Assistance Services important?

Contributors emphasised the importance of personal assistance services in enabling people with a disability to function in society in such a way that they had a real life, could play a part in society and live like other people do. PAS provide the freedom and support to allow or enhance independent choice and opportunities. With this service, a person with disabilities can enjoy privacy, choice and control. To be able to live independently and be part of society like other people is the difference between living and existing.

The ability to live in one's own home in the community was another benefit of the personal assistance service that contributors considered important. The ability to do simple but essential things, like have a shower or go to bed, to have a greater choice in how or where one could do such things, was stressed.

The support of a personal assistant enabled people to participate in education and have an opportunity to progress to employment or in the workplace. Without these supports, many people would not be able to go to college or enjoy a social life.

As well as allowing the person with disabilities to live as independently as possible, by assisting in day-to-day living a personal assistant can also allow the person's family to take a back seat. In personal terms, a PA may build up a relationship of trust with their client where they work very well together. They become indispensable in the life of the client.

A person's outside social life may also depend on the support of a personal assistant, giving independence and preventing isolation. One contributor listed the many things they would not be able to do without their PA; get out to the shops, go to the gym, post a letter, go to the doctor or chemist. Without the PA they would be totally dependent on others and 'miserable', this person said. In the words of another contributor, 'they are my hands and legs'. The service gives great hope and value and enables people to participate more in society than would be possible if living in a residential setting.

‘Quite simply it allows people with disabilities to be people – to live real lives with real meaning.’

Question 2: What are the key elements of a good-quality Personal Assistance Service?

The responses to this question made points on management, training, resources, individual relationships between Leader and PA, and also between people and service providers, personal qualities required and the right fit between personal assistant and Leader. Above all, they emphasised respect for the person with disabilities, their active participation as much as possible in directing their support services and provision of a service centred on their needs.

A good service would support the person with disabilities to imagine a life without limits with the help of a personal assistant. It would take it as given that all people with a disability could decide, with or without help, to have as much control as possible over their own lives and in directing their service. It would help the Leader to self-assess their needs and put a plan in place to maximise their lives. Through training, it would help the Leader to develop an understanding of their role in managing their PA. In the same proactive way it would help to ensure that people working as PAs had a full and in-depth understanding of independent living and were comfortable with the Leader deciding what happened in the different aspects of their lives; home, work and socially. Where required, it would advocate for increased hours. In summary, it would always be concerned with meeting the needs of the Leader.

This person-centred approach would require good management and that management would need to ensure training for staff and personal assistants. Leaders would also need training to prepare them for managing and receiving the personal assistant’s services in an active and appropriate way. The onus was not just on the personal assistant to take directions but also on the Leader to give directions with confidence, something that training could help to ensure.

While training for personal assistants and Leaders was necessary, views differed on what form such training should take. Some Leaders felt that very structured training, such as courses to FETAC Level 5, would not meet training needs.

For self-directed services to work best, flexibility, trust and the ability to really listen to the Leader as client would be needed. Mutual respect was important.

The theme of respect and personal power ran through the responses. This applied to both individual PAs and to management or service providers. A good personal assistant would be patient, kind, caring, attentive, a good listener, conscientious, motivated, determined, obliging, helpful, have a good personality and be open to ideas. Being trustworthy, honest and respecting confidentiality were other important attributes. Finding the right match between PA and Leader would be best achieved by the Leader playing an active role in selecting the PA that suited best.

Managers of PA services needed to respect the client since without the client there is no service. The role of the personal assistant as employee of a service provider raised a very important issue, that boundaries were needed between 'judgement' of a client and 'reporting' to the HSE and genuinely working with a client to address issues as they arise.

One Leader summed up this point in the following words:

'Dare to raise an issue and I have found the less able managers then prefer to 'eject' the client from the service after 'blaming' the client for the issue however clear it is that it is an inadequate system that creates most problems. I have personally obtained copies of all my HSE notes and have been horrified at the inaccurate, judgemental and highly subjective comments which are now a part of my health records, yet I was not asked to comment or provide a client perspective. [It is] a form of bullying and a huge lack of respect. How many more people is this happening to and they don't know it? It is very upsetting to read such comments. In effect, the PA becomes a 'spy' in one's home, even though they have no intention of being used in this way'.

A good-quality personal assistance service needs resources, both to offer good pay and back-up support, such as relief cover, to personal assistants and to provide enough hours for the client in cases of holiday cover or emergencies. The number of hours provided would depend on each person's needs.

Within the overall structure of personal assistance services, good communication between Leaders and the Center for Independent Living and strong participation at all levels of CIL, especially board level, by those who have the skills, were essential.

Question 3: Are the application and assessment processes for PA services accessible, fair and user friendly?

Views differed on this question with a small majority of contributors expressing satisfaction and others not. Certain flaws in the system were identified. The important question was asked, what is driving the process; is it funding, staff or other concerns of the service provider or the needs of the person with disabilities? One Leader found the process was fair but 'not firm enough'. Another person had found it fair with the help of a public health nurse but that it was difficult to find the right service to suit them so that linking with people who had a similar disability was important.

Two comments detailed the flaws in the process as people had experienced it:

'The provider I am familiar with is funding and staff led. While it can't control the lack of funding, it can enhance the process of empowering people with a disability to know what their world would look like with all their needs met. People with a disability don't have a clear process into assessment or what they can ask for. Fear and secrecy is at the heart of too many people's lives and [this is] reflected in how they engage. The service provider generally does not address this adequately'.

The second detailed comment went beyond the person's own experience to the national situation:

'[It is] not accessible. [The] district nurse made [the] initial request. [A] Letter came back saying "no" and no assessment [was] undertaken. Later in the year, hours were approved as I was in hospital for several weeks and it enabled me to come home. [It is] definitely not fair or user friendly. I regard the system as one in which the client is 'done to' – the assessment process is highly subjective. Recently, I have obtained copies of PSDS policies from different parts of the country. Not only is the assessment subjective, based on assessment tools from 1965, in terms of policy it is biased on a geographical basis and depends on the skill and judgement of those handling the budget at local level'.

Question 4: Have you experienced long waiting times before or after assessment?

Most contributors had not experienced long waiting times. In the case of one person, once they had successfully suggested their preferred service, they had been 'lucky once the funding was available'.

Of those who had experienced delays, one said it had occurred a long time ago but not recently while another 'sometimes' found delays. One respondent recounted a delay in assessment to increase their package, 'after which it has to wait for "the Committee" to meet'.

Question 5: Is there consistency amongst service providers in terms of quality of service provision?

The majority of people said there was no consistency in quality of service. Two said there was. Others could not comment as they had or 'were allowed' only one provider and had found this a positive experience.

One Leader, with experience in education, found the standard and practice of managers unsatisfactory and unacceptable. They had been with four different service providers, one of which had gone out of business while others had struggled to find carers. Another contributor found that, while some services said they catered for a particular need, 'once you are in it the reality can be different'. This Leader repeated the importance of peer support that had been made in other themed discussions, as it could give some advice on which services might meet a person's needs, though it was accepted that this wasn't always easy given that each person's needs were different.

Question 6: How can services be improved?

Contributors made proposals under a wide range of headings, such as standards, monitoring, accountability, information, peer support, training, payments and wider service

options. The importance of formal participation by Leaders in the system was repeated many times with training and direct funding cited as ways of enabling this.

At the most basic level, more funding for services and direct payments to people with disabilities to enable them manage their individual supports would improve services.

Consistent, countrywide standards are needed with accountability assured through a framework of monitoring and ongoing assessment. This system of accountability should be centred on the needs and outcomes for the client. Service providers should show they adhere to the values of independent living for their clients in tendering for contracts. Evidence of independent living outcomes, based on evaluation, should be central to the awarding or loss of contracts for service providers.

People with a disability should have greater options in service providers and more organisations should be able to tender for contracts. One respondent said some organisations had too much monopoly in the allocation of contracts and proposed a rule limiting the maximum number of contracts allowed to a particular company.

Giving Leaders access to their own individual funding would also give people with a disability more control in managing their services, as well as their wider lives. Clients should be accountable to the HSE for their use of funds. Again, if Leaders could take a formal role in assessment and delivery of services such services would be more responsive to individual needs.

Training, information about services and more peer support would equip Leaders to play an active part in securing and managing their PA service. One contributor suggested that participation by people with a disability should be compulsory and supported by training. A good-quality service would allow personal assistants to support clients to go out and mix socially. Peer support and face-to-face involvement in groups would give clients access to valuable advice and experience, although phone or online peer mentoring would be helpful too. One Leader recalled:

‘There is nothing more valuable than advice and talking to others with similar experiences. Coming out of rehab, I felt really low. Meeting people who had gone through a similar process gave me hope for a positive future’s

Question 7: What do you think the value of using direct payments to access PA services is?

Contributors to this discussion saw great merit in a system where those with a disability could directly employ their personal assistant and shape their services to their particular needs. It was seen as giving the person control, with responsibility, and access to wider service options.

Such autonomy would confer dignity on the individual and ensure greater respect from service providers but it would have the practical benefit also of putting service users on an equal footing with service providers. If clients had control over their individual budgets,

standards would improve since clients could take their money elsewhere. It would strengthen a Leader's hand when problems arise, removing the fear that complaining would lead to a loss of service.

With direct payments, people could employ their own personal assistant and decide when, where and how the service should be provided. Such control would ensure services were matched to the person's needs.

Although forum members saw direct payments as the way services should go, they also recognised some of the disadvantages. Some felt there was misunderstanding over the implications of direct payments for clients. Greater autonomy would mean more work since the person with disabilities would have to manage their budget and service arrangements. At present, with no legal system of direct payments, people have to create their own company or trust in order to avail of the option, which involves paperwork and legal regulations. Not everyone is able or willing to do this.

One person felt it would put pressure on the Leader to do training in how to run their service. Another contributor thought it a good idea but that it would only benefit a few people with disabilities as many others lacked the skills of people management, human resources or conflict resolution. A good idea, said another Leader, so long as people get their money on time. The prevailing view was that it is a good system, so long as the person wants it and is able to manage the extra work and responsibilities.

Question 8: What supports are required for Leaders and PAs for effective Personal Assistance Services?

Leaders need support for every step of the process from assessment to employing their personal assistant but they also need help in understanding their emotional response to their situation. Families need to be supported throughout too.

More resources are needed if personal assistance services are to be effective – money, hours, transport, holiday cover and enough high-quality personal assistants. An ombudsman was also suggested and legislation to give people with disabilities legally guaranteed rights.

Overall, there is a need for more and frequent training and for guidance and advocacy in line with the philosophy of independent living. Both Leaders and personal assistants needed practical training in all aspects of what is entailed in independent living. The person with the disability needs to be clear about the service they require and the personal assistant needs to respect that the leader is in charge and must have full control over the service.

People stressed the importance of good communication between Leader and personal assistant, with honest feedback and open lines of communication so that problems can be aired and solved.

Access to phone support would be important and office staff who could discuss problems and give back-up when needed. One person suggested the AT Network (Note: The AT

Network or Áiseanna Tacaíochta is the first and main organisation to facilitate direct payments to PWD in Ireland) as a model, having found it very helpful and supportive.

‘I would love to meet everyone but the distance and lack of PA support to leave my home makes it impossible. Maybe, as this model expands, more Leaders meetings could take place in different geographic locations.’

Question 9: How important do you think it is to have legislation around PA services and why?

Legislation was seen as essential to protect services against funding cuts and economic changes by guaranteeing access to services as a legal right.

The scope and quality of service may vary depending on where one lives. Legislation would ensure fairness and equal access to services and prevent problems arising. Legislation providing specific aspects of services, such as a direct payments system, was also necessary.

At present the personal assistance service depends on the allocation of government funding and available resources. Leaders said that the Department of Health and the HSE had different definitions of a personal assistant but in practice there was no access to full personal assistance services because too few hours are allocated to a person with disabilities to allow their PA to carry out the full role.

Legislation would protect also the personal assistant who deserves the same rights and ability to earn their living as other employees.

Leaders believed a person with a disability could only be really heard if legislation were in place. Legislation empowers and encourages responsibility. Without legislation, promises of services are all but meaningless.

‘I believe it is very important to have legislation for personal assistance services as we are all citizens. It should be a human right for people to have this service as we can live independently and give back to society as a whole and not have to hear those words “subject to funding”.’

Question 10: What actions would you like CIL to take on these issues?

Suggestions for action by CIL focused on three areas – law and lobbying; support for people with a disability; and promoting higher standards. Lobbying should be directed at securing a legal basis for personal assistance services and to set up a direct payment system. CIL was urged to employ effective lobbyists in pursuing this campaign. The presence of a TD, either able-bodied or disabled, who would represent the disabled population in the Dáil, would be an advantage.

CIL was urged to train Leaders on how legislation is developed and influenced and on how to lobby for positive change. Leaders should be supported to take up positions of influence so

they could lobby for change, helped to work together in a unified approach and reimbursed for money spent on representing Leaders or CIL.

In terms of supporting people with disabilities, the following suggestions for priority actions were made: to educate more people with a disability on how a personal assistant could enhance one's life; to update Leaders on what CIL is doing; and to continue to organize peer support group meetings so members and their PAs could have a chance to meet. CIL should advocate for each and every one of its service users, one contributor said.

However, one person pointed out that many CILs are so busy delivering personal assistance services and complying with HSE service level agreements, new policies and procedures that time is an issue for them. This contributor suggested that people with disabilities who were not directly involved in a CIL but looking for or in receipt of PA services should help make progress on this issue.

Suggested actions for establishing standards were focused on HSE and service providers, and on personal assistants. CIL was urged to gather and document information on bullying as evidence of existing practice. It should set out and seek criteria to ensure the HSE and personal assistants could be made accountable for poor-quality practice. Further, gathering information on the hours given to people in different areas would help to identify inequalities in personal assistance services.

In assessing services and seeking improvements, the client must be at the centre of the process. The partnership between the client and the personal assistant should be the driving force of any new model, rather than service managers, as it is the personal assistant who works day-to-day with the client in the home. Few service managers have this direct working experience.

One Leader said that the manager's role was to enable the client and the personal assistant to work together but that was not the model for doing things at present.

CIL was urged to set up a database of personal assistants that clients could search. This, coupled with direct payments, could be part of a new personal assistance services model.

One response asked what had happened about a draft Bill that CIL had proposed and held consultation meetings on before. This person questioned why would the Government listen to the Center for Independent Living, who did it represent and what governance did it operate from?

2.5 Key Recommendations

- Continue to advocate for implementation of legislative protection for personal assistance services;
- CIL to advocate for and raise awareness of personal assistance services and the philosophy of independent living;
- Improved communication between CIL and Leaders;

- Training and empowerment of Leaders to take active roles within the organisation in relation to advocacy, with specific training on influencing decision making and policy change;
- Support and train Leaders as lobbyists;
- Develop resources to support Leaders to actively manage their personal assistant and take a leading role in service development;
- Training for PAs on the independent living philosophy, the social model of disability and the Leader-led approach;
- Communications training for PAs and Leaders;
- Establish a body of information in relation to bullying;
- Address inequality and inconsistency in service provision based on geographic location;
- Propose a model of criteria for the management of the service to ensure that there is true accountability for poor-quality practice and service at all levels;
- Advocate for Leader-centred, client-focused supports while acknowledging the diversity amongst Leaders;
- All staff involved in management and delivery of PAS should administer their roles based on the person-centred approach;
- Support the extension of direct payments and develop a database of personal assistants to support Leaders to identify appropriate and suitable PAs;
- More consistent practical training for both PAs and Leaders nationwide;
- Partnership with Áiseanna Tacaíochta to raise awareness of direct payments;
- Co-ordinate insurance so that PAs can use their cars in the course of their work;
- Develop peer-led supports through group support, peer mentoring and phone support;
- Ring-fence the funding of PAS within the wider HSE budget;
- Increase supports to small organisations to deliver PAS regionally;
- Increase the PAS budget to allow more people with disabilities to avail of PAS;
- Deal with the waiting list for PAS. This is currently at 1,600 and is equal to the number of people in receipt of PAS;
- Raise awareness of PAS and simplify the application process to ensure that PAS become a realistic option for people with disabilities;
- Establish universal quality standards for service delivery of personal assistance services for all organisations and private companies nationwide;
- Restoration of services in line with the restoration of pay for civil servants;
- Expansion and development of direct payment support services like Áiseanna Tacaíochta;
- Leaders have choice over which service provider delivers their personal assistance service;
- Nationwide standardisation of application and assessment procedures;
- Funding for PAs to undertake travel activities with the Leader;
- Allow PA hours to enable PAs to help Leaders train for sporting activities;
- Create clarity on the issue of PAs supporting Leaders in their roles as parent;
- PA supports for personal care including injections and first aid;
- Seek clarity on the administration of medications especially in relation to insurance cover;
- Abolish the social welfare means test. Everyone should be entitled to PAS and support with transport irrespective of means;
- Ensure the Leader directs the service and provide support to enable those with a mental health or learning disability to do so;
- Employer-employee relationship should be defined in terms of boundaries and management;

- PAS entitlement should not be based on income. It should be a right irrespective of means;
- Provision of service should be based on need, not hours;
- PAs to be trained in advance of taking up role;
- CIL to design and deliver PA training programmes;
- Training to facilitate diversity in Leaders' lifestyles and needs;
- Training should be Leader led;
- Social needs to be considered in assessment;
- Irregularly occurring, seasonal and emergency hours should be included in PAS;
- Provide support for new Leaders in managing services. This could include something along the lines of 'trustees' or micro-boards with more focus on control being in the hands of the Leader;
- Have a multi-departmental approach to provision of services;
- Any proposed Bill or legislation should include the option of a direct payment system as opposed to management by designated organisations;
- The language of any legislation or Bill should focus on self-determination and on the Leader being an active participant and should not consider the person with a disability as a dependent;
- Universal remuneration for personal assistants;
- Tenders to be carefully monitored to ensure all service providers meet minimum standards;
- Every CIL should have a peer support officer to provide support to Leaders;
- If family provide emergency respite, they should be remunerated;
- The Leader decides who will provide emergency respite;
- The Leader should choose who the PA will be.

PERSONAL ASSISTANCE SERVICE BILL 2013

As Initiated

ARRANGEMENT OF SECTIONS

PART 1

Preliminary and General Section

- 1: Short title, collective citation and commencement.
- 2: Definitions.

PERSONAL ASSISTANCE SERVICE BILL 2013

BILL

An Act to provide people with disabilities with the necessary assistance to live and engage independently as members of society in equal measure to their non-disabled peers and to prevent and eliminate the disadvantages and obstacles caused by society and by doing so to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

WHEREAS the aim of the National Disability Strategy is to support equal participation in society for people with disabilities,

WHEREAS the Programme for Government commits to ensuring ‘that the quality of life of people with disabilities is enhanced and that resources allocated reach the people who need them’ and further that it will ‘facilitate people with disabilities in achieving a greater level of participation in employment, training and education’,

WHEREAS Article 19 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) provides:

‘States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to 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;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.’

WHEREAS at paragraph 129 of Ireland’s National Report to the Working Group on the Universal Periodic Review delivered in October 2011 the State committed to ensuring ‘that people with disabilities are assisted to live full lives with their families and in their communities’,

WHEREAS Personal Assistance Services facilitate the full participation of people with disabilities in society,

BE IT ENACTED BY THE OIREACHTAS AS FOLLOWS:

PART 1

Preliminary and General

1. – (1) This Act may be cited as the Personal Assistance Service Act 2013

(2) This Act and the Social Welfare Acts may be cited together as the Social Welfare Acts and shall be construed together as one.

(3) This Act comes into operation on such day or days as the Minister may appoint by order or orders either generally or with reference to any particular purpose or provision and different days may be so appointed for different purposes or different provisions.

2. – In this Act ‘Minister’ means the Minister for Social Protection.

Section 2

The person with a disability

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Section 3

The purpose of Personal Assistance

Personal Assistance is the necessary assistance required by a person with a disability to ensure that he or she can participate as a full and equal member of society.

Personal Assistance is directed by the Leader and responds to the needs of an individual as they arise, inside and outside of the home, throughout the life cycle of the individual. The purpose of Personal Assistance is to ensure people with disabilities enjoy the same opportunities as all members of society, to ensure they have the same choices as others, and to afford them the means to control how they wish to pursue their lives.

Personal Assistance is applicable to aspects of personal care, domestic duties, family life and inclusion, and in places of work, education and training.

‘The Leader’ means a person with a disability in receipt of personal assistance service.

‘Personal care’ means assistance getting up and going to bed, assistance during the night, dressing and undressing, personal hygiene and grooming, assistance using the toilet and in the bathroom. Assistance preparing food, cooking, eating and drinking. Assisting in areas of personal care the nature of which may be considered clinical or paramedical in nature including, but not exclusively, such matters as assistance to prepare and administer medication, assistance with bladder and bowel programmes, PEG-feeding, communication and interpretation, alternative communication devices and whatever other means.

‘Maintaining the Home’ means all tasks associated with the maintenance of a family home such as cleaning, washing, laundry and shopping, together with assistance with looking after children.

‘Social Activities’ means all activities associated with socialising with family, friends and in the community. Personal assistance may include accompanying the Leader while visiting, travelling or while on holiday. Assistance using public and private transport including driving, interpretation and communication. Assisting an individual to develop and maintain social interaction.

In terms of Education and Employment, personal assistance includes assistance getting to place of work, education and training, and assistance at such locations.

(1) Activities associated with the maintenance of one’s health and well-being such as self-care or physical exercise, or undertaking therapy programmes under the supervision of a professional therapist where appropriate, which one would normally carry out for oneself, are tasks which can be performed by Assistants after appropriate training by appropriate clinical, medical or paramedical staff if deemed necessary. Some of the tasks in this area may require specialised training. National protocols will be developed for certain specialised tasks which will be mandatory for service providers.

(2) Personal Assistants may be required to assist an individual with intellectual disability to develop and maintain social interaction within their local community and to give structure.

Section 4

Eligibility for Personal Assistance

A person with a disability shall be eligible for personal assistance where such personal assistance is necessary to enable that person to engage fully and effectively in society.

In such a case that person may apply to the Department of Social Protection or other appropriate Government Department as set out in Section 5 for an assessment of the hours of Personal Assistance necessary to sustain the equality of opportunity in their daily lives.

Section 5

Assessment for Personal Assistance

The Department of Social Protection shall have responsibility for ensuring individual needs are assessed which shall be expressed in the number of weekly Personal Assistance hours necessary to enable the individual to live an independent life and to participate fully in society.

On receipt of an application from an individual, or a recognized supporter of that individual, for a Personal Assistance Assessment, the Department shall initiate the assessment process within twenty-one days.

A decision concerning the number of hours of assistance shall be made without undue delay and within a time not to exceed three months from the receipt of application, unless for reasons specified the application requires a longer time period.

The Personal Assistance Service Assessment Officer (1), who shall be approved by the Department of Social Protection but who shall be independent of that Department, will have detailed knowledge of person-centred planning (2) and the philosophy of independent living (3).

Assessment of Personal Assistance hours will be made without regard to any upper limit on the number of hours and without regard to the cost of the service or the means of the individual.

The Assessment Officer shall have regard to the number of hours required by an individual as determined by that individual through a process of self-assessment (4) having regard to regularly occurring routine activities including assistance with travel.

Applicants will have access to third parties for support, such parties to include advocates and peer mentors, prior to any assessment. Applicants are entitled to be accompanied by an advocate during the assessment and at any subsequent appeal.

An Appeal of a decision of an Assessment Officer shall be made to the independent personal assistance appeals board and shall be made within 14 days of the date of the decision (5).

The Department of Social Protection shall ensure the quality of assessment by establishing national criteria for assessment of individuals and by contracting suitably qualified and experienced persons who will be obliged to undergo mandatory training to FETAC level 5 or its equivalent.

(1) The Assessment Officer and the Department are required to be separate entities to avoid any undue pressure caused to Assessors arising from any restriction of funds for the purpose of providing personal assistant hours.

(2) For the purpose of this Act, Person-Centred Planning is a way of organizing supports around a person, in consultation with that person, to define and create a self-defined future for him or her.

(3) Independent Living is the emancipatory philosophy and practice which empowers people with disabilities and enables them to exert influence, choice and control in every aspect of their life.

(4) Self-assessment is based on the description by an individual of their everyday life. All regularly occurring activities should be included in the assessment. The assessment should be based on that description.

(5) During the assessment process Leaders are informed about their rights to appeal assessments. The appeal procedure is clear and straightforward, inexpensive to the assistance user, and includes several instances including courts of law.

Section 6

Organisation of Personal Assistance

The Department of Social Protection or other appropriate Government Department shall be responsible for the organisation and funding of Personal Assistance (1).

Individuals who qualify for a personal assistant service under the Act can receive their assistance:

- (a) from a registered provider procured by the Department for that purpose (2),
- (b) by way of a direct payment for the purpose of enabling a qualifying individual to procure their personal assistant service from a registered provider (3),
or
- (c) by way of a direct payment to the qualifying individual to cover the cost of employing a personal assistant including wages and other reasonable and necessary costs associated with the employment of an assistant (4),

or

(d) through a combination of the above (5).

Individuals who choose to organize their service through a direct payment shall be provided with the expert professional assistance required to enable them make decisions and to administer direct payments (6).

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- (1) Recognising that Personal Assistance Service is a key constituent which gives effect to the philosophy of independent living and self determination, and is a human right, the responsibility for the organisation of personal assistance services should not be that of the Department of Health. Therefore Personal Assistance Services shall be under the remit of the Department of Social Protection or other equivalent government department.
 - (2) All organisations providing personal assistant services shall be registered providers and meet the criteria as set out by the Department of Social Protection.
 - (3) A registered provider under the purposes of the Act may be a private commercial company, a not-for-profit company with charitable status, a group of supporters registered as a limited company (e.g. a micro-board or similar type entity), a collective entity registered as a limited company (e.g. a co-operative).
 - (4) Individuals who choose to self employ are subject to all of the provisions which relate to employers. Individuals must register as employers with the Revenue Commissioners. Individuals may register as Limited Companies or Sole Traders but are not obliged to do so. Direct payments for the purpose of employing a personal assistant are not deemed as income for the purposes of taxation.
 - (5) Individuals may choose to receive their personal assistance service in part from a registered provider or providers, and in part by directly employing assistance services.
 - (6) Where qualifying individuals choose to receive their service from a registered provider the provider is accountable to the appropriate department for the hours of service delivered. In the case where a qualifying individual chooses to be the employer the individual is accountable to said department.

Section 7

Qualifying as a Personal Assistant

A Personal Assistant shall be anyone trained to FETAC level 5 or its equivalent and deemed qualified by the Leader in receipt of the service but shall exclude persons specified in paragraph (b) unless –

- (a) in the case of a service mentioned in Section 3 the appropriate government department is satisfied that securing the service from such a person is necessary to meet satisfactorily the prescribed person's need for that service.

The persons specified for the purposes of paragraph (b) are –

- (b) 1. The spouse of the prescribed person,
2. A person who lives with the prescribed person as if his/her spouse,
3. Persons living in the same household as the prescribed person who is the prescribed person's:

- (i) Parent or parent-in-law;
(ii) Son or daughter;
(iii) Son-in-law or daughter-in-law;
(iv) Stepson or stepdaughter;
(v) Brother or sister;
(vi) Aunt or uncle; or
(vii) Grandparent.

4. The spouse of any person specified in paragraph (b) who lives in the same household as the Leader.

Persons specified in paragraph (b) may act as a personal assistant for the prescribed person if they are employed to do so by an organisation which is independent of the Leader.

The rate of payment per hour of personal assistance is determined through national agreement.

Hourly rates will vary in accordance with the categories set out;

- a) Sociable Hours 8am – 8pm
b) Anti-social Hours Bank Holidays and weekends
c) Sleepovers
d) Aspects of Personal Care as set out in Section 3 (1).

The rate of payments per hour for the provision of personal assistance to a service provider or directly to a service user will include the hourly rate of pay per service hour type as agreed through national agreement including holidays and bank holiday pay, holiday and sick leave cover.

Other reasonable costs associated with employing a Personal Assistant to include: employers PRSI, public liability insurance, employers liability insurance, administration overheads, payroll and accounting services.

PART 2

Amendment of Existing Legislation

Appendix 2 Leader Forum Consultation Feedback Questions

1. Why are Personal Assistance Services important?
2. What are the key elements of a good-quality Personal Assistance Service?
3. Are the application and assessment processes for PA services accessible, fair and user friendly?
4. Have you experienced long waiting times before or after assessment?
5. Is there consistency amongst service providers in terms of quality of service provision?
6. How can services be improved?
7. What do you think the value of using direct payments is?
8. What supports are required for Leaders and PAs for effective Personal Assistance Services?
9. How important do you think it is to have legislation around PA services and why?
10. What actions would you like CIL to take on these issues?

Seanad passes motion on Personal Assistance Service, 7th May 2014.

That Seanad Éireann:

- Notes that Article 19 of the United Nations Convention on the Rights of People with Disabilities (UN CRPD) provides that States should recognise “the equal right of all persons with disabilities to live in the community, with choices equal to others” and commits States to “take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community”;
- Notes the commitment in the Programme for Government 2011 to ensuring “that the quality of life of people with disabilities is enhanced” and further that the Government will “facilitate people with disabilities in achieving a greater level of participation in employment, training and education”;
- Notes that the aim of the National Disability Strategy is to support equal participation in society for people with disabilities;
- Notes further that the provision of Personal Assistance Services can facilitate the full participation of people with disabilities in society;
- Acknowledges the progress made by the Government in respect of the Programme for Government commitments on facilitating the full participation of people with disabilities in society, particularly in:
 - the publication of the Value for Money and Policy Review of the Disability Services which will lay the foundations for a new system of individualised budgeting, which will allow people to exercise greater

choice and control, enabling them to live fully inclusive, active and independent lives within the community;

- the publication of an implementation plan for the National Disability Strategy;

- the development of a comprehensive employment strategy for people with disabilities, which will be published this year as set out in the Action Plan for Jobs 2014.

- Calls on the Government to support the provision of a 'Personal Assistance Service' within the overall framework of the migration to a person-centred supports model, in order to provide people with disabilities with the necessary assistance to live and engage independently as members of society in equal measure to their non-disabled peers.