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**ILMI**

INDEPENDENT LIVING  
MOVEMENT IRELAND

# LEADER MANUAL

Freedom | Choice | Control | Independence





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# LEADER MANUAL

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Nothing about us without us



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A person is walking on a paved surface, using a white cane. The person is wearing dark pants and shoes. The cane is white with red reflective bands. The background is a light-colored paved surface with dark lines.

# Foreword

“Independent Living is about having control over your life: to have a family, to get a job, to participate socially and to realize whatever goals and dreams you set for yourself. ”

## Foreword

*Independent Living is about having the freedom to have the same choices that everyone else has in life. Independent living is about choosing what aspects of social, economic and political life people want to participate in. It is about having control over your life: to have a family, to get a job, to participate socially and to realize whatever goals and dreams you set for yourself.*

**At the core of the Independent Living philosophy is living like everyone else: being able to have control of your life, having opportunities to make decisions and being able to choose activities that you want to do, regardless of impairment.**

For many disabled people, Independent Living can best be achieved with support from the Personal Assistance Service (PAS), which was originally brought to Ireland by CIL in 1992. The PAS enables us to do all the tasks that we cannot do for ourselves. It provides us with the freedom and flexibility we need to live our lives as we chose. A Personal Assistant (PA) is hired to assist us with a range of day-to-day tasks that we cannot physically do for ourselves. With PAS we are in control and direct the PA to carry out tasks both inside and outside of the home. A PA does not “look after” or “care for” us. We delegate these tasks to our PAs and in doing so take back control of our lives. A distinct benefit of PAS is that it reduces our dependence on our family and friends. The confidential relationship that develops between our PAs and us allows us to maintain a private life and our dignity. The PAS is often the difference between existing and living for many of us.

ILMI understands that being a disabled person leading your PAS is a complex and demanding role. In many respects the responsibilities that come with managing your PAS have increased through the years. Recognising this Independent Living Movement Ireland (ILMI) developed this Leader Training Manual to empower Leaders to lead their service with confidence.

It was developed through consultations and general discussions with experts on PAS – Leaders themselves who are active within the Movement.

This Leader Manual is targeted at Leaders of their own Personal Assistance Service or those who aspire to do so. It can also act as a really important resource for Personal Assistants (PA) who are directed by Leaders or for someone considering becoming a PA. Inherent within the Manual is recognition of the role family members play within the PAS and we believe that individual family members may also benefit from its content.

On behalf of ILMI I would like to thank all the Leaders who were involved in discussions on PAS and Independent Living, which led to the development of this resource. Adjacent to this document is a Leader Training course, which ILMI work to provide to disabled people who wish to learn more about the PAS. I want to recognise the role of James Cawley (ILMI Policy Officer) and Eileen Daly (ILMI Member) who have already delivered this training as a pilot programme to bring this resource to life.

I especially want to recognise the role of Susan O'Brien (ILMI Development Officer) for bringing this resource together. We in ILMI team hope that both the Leader Training and Leader Manual will be of great benefit to many disabled people and their families long into the future.

*Shelly Gaynor, ILMI Chairperson*

A person with dreadlocks is sitting in a wheelchair on a sandy beach, looking out at the ocean. The background is slightly blurred, showing the waves and a bright sky. The person is wearing a dark shirt and shorts. The wheelchair is a standard manual model with large rear wheels and smaller front wheels.

## Section 1

# Independent Living

“Independent Living isn’t about ‘them and us’ it is about everyone together in an inclusive society”.



## Independent Living

*Independent Living is about equal rights and opportunities; it is about the freedom to choose and the right to make decisions for all things, which affect one's life.*

**Independent Living aims to give us the control over our own bodies and lifestyle that others take for granted. It is not about being able to do everything for ourselves but rather about giving us the freedom to control the assistance and supports, which we need to live independently.**

### The History of Independent Living

Independent Living first came to fruition when a student with a disability, Ed Roberts, was admitted to the University of California in Berkeley. In 1969 he and several other students developed a programme of support services, which would enable severely disabled students to live independently. As these students neared the end of their academic career it became evident that a similar service would need to be put in place in order for them to continue living independently in the community and the first Centre for Independent Living (CIL) was established. It was built on the belief that:

- We should have the same rights as non-disabled people.
- We know best how to serve and empathise with similar disabled people.
- We should have the same right to choose how to live our own lives and to succeed or fail on our own.
- We can achieve an effective measure of independence only if we are actively engaged in the process.

In 1992 the first CIL in Ireland was set up by and for disabled people in response to the lack of choices and control that people felt they had over their lives. Today CILs across Ireland continue to address many of the elements necessary to the achievement of Independent Living including Personal Assistance, Housing, Transport, Access, Training and so on.

***"We are the experts in our own lives, we know what needs to change and in ILMI we will build an organisation that empowers disabled people to collectively lobby and campaign for that change."***

*Michelle Gaynor, ILMI Chairperson*

# The Social Model of Disability

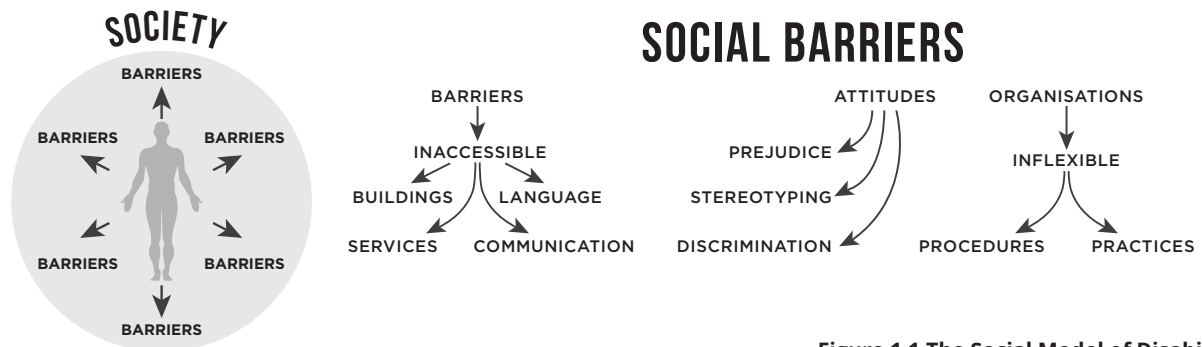


Figure 1.1 The Social Model of Disability

## How People View Disability

Disability is often seen from two different perspectives: the medical model and the social model. Through the medical model disability is understood as an individual problem. It is seen as a condition of people who have difficulties arising as a result of their impairments. If somebody has an impairment - a visual, mobility, or hearing impairment, for example - their inability to see, walk, or hear is understood as their disability.

With the social model disability is viewed as an issue that arises from the barriers we face in society rather than our own medical issues. It recognises that disability affects every part of our lives not just our health. Under the social model we are excluded from fully participating within society as a result of physical, environmental and attitudinal barriers which prevent us from gaining equal access to education, employment, information, housing, public transport, leisure opportunities, and so on.

Using the social model, disability is no longer seen as an individual problem but it becomes an issue that needs to be addressed at every level: social, economic and political.

Independent Living has emerged from the move towards the social model of disability. People realised that we were disabled by society and the inaccessible environments in which we lived and the assumptions that other people made about us based upon our impairments. A movement arose against the practice of identifying disability as a 'problem' that required a 'special' treatment or service. By focusing on the barriers to participation rather than the individual's disability a gradual shift toward the social model began.

## Exercise 1: Independent Living Review



### **Fact or Fiction?**

Read the following questions and tick the option you think indicates the correct answer (there may be more than one correct answer):

**1. The Independent Living Movement in Ireland was influenced by events in which country?**

- France
- Denmark
- America

**2. Independent Living is:**

- Someone else doing everything for us
- Doing everything for ourselves
- Controlling the supports that we need

**3. When was the first CIL established in Ireland?**

- 1969
- 1982
- 1992

**4. The Social Model of disability believes that:**

- Our disability is an individual condition
- Barriers we encounter in society disable us
- Disability needs to be addressed at all levels of society

**5. Independent Living comes from:**

- The social model of disability
- The medical model of disability
- The human rights movement

## Section 2

# Personal Assistance Services

# Personal Assistance Services

***Personal Assistance Services gives us choice and control over our lives by supporting us in a range of daily tasks, which enables us to live an independent life.***

**Personal assistance empowers us to live our lives by removing dependence on others. By contracting the services of a Personal Assistant we can decide who supports us, in what ways, and at what times. It gives us control over our own lives.**

## **What is a Personal Assistant?**

A Personal Assistant (PA) is employed to provide us with assistance to live independently. A PA is not a carer. A PA assists us in all aspects of daily living. We delegate tasks that we may not otherwise be in a position to do, to a PA. The assistance provided depends on our needs therefore there is no standard 'one size fits all' Personal Assistance Service (PAS).

A PAS is distinct from other types of assistance in that s/he provides assistance with personal care, household tasks, and communication within the home but can also provide us with assistance outside the home environment to allow us to continue living within our local community by attending work, education and other social activities. PAS puts the person at the center of the service and is focused on me as opposed to the task.

Typical areas of work that a PA would assist with may include:

- Domestic: laundry, shopping, meal preparation, light housework, driving, etc.
- PA to assist with general maintenance or day to day running of your equipment. Otherwise contact your OT
- Personal care: bathing, showering, help with toileting.
- Social: banking, going out to the pub/concerts, meetings, etc., communication.
- Lifestyle: if you are in employment or education any assistance you may require in these areas as well.

## **What is a Leader?**

Leader is the term used to describe a disabled person that manages his or her own PAS. As Leaders we are involved in every stage of the PAS service including recruitment of our PA where possible. We direct the PAS appropriate for our needs. Our role is to direct the PA in performing the tasks that enhance our independence. As Leaders we would generally work on a one-to-one basis with a PA in our home, college or workplace. We need to be able to direct the PA in what needs to be done and when it needs doing. A PA may not have all the training or experience required prior to their appointment therefore we must be capable of training, supervising, instructing and communicating with our PA accordingly.

The term Leader is often used interchangeably with the term client or service user. However core to the term is the understanding that I am directing the tasks I require to live my life and therefore I have control over it.

***"Personal Assistance Services are my arms and my legs. It has brought normality back into my life and has proven the difference between existing and living"***

*PAS user, Roscommon*



## Your Service Provider

In Ireland the budget allocated to the majority of PAS is administered by the Department of Health through the Health Service Executive (HSE) in nine Community Healthcare Organisation (CHO) areas. The HSE administers the budget in each CHO area through local service providers such as the Irish Wheelchair Association, Centres for Independent Living, Bluebird Care, Enable Ireland and many other providers. There are also schemes provided by Intreo through the Community Employment Scheme and the Department of Education for students in third level education. Some individuals also chose to privately contract PAS. There is no uniform assessment of need and the service provided in each CHO area may differ greatly even when the level of individual need remains the same.

There are also many different types of PAS including: self-directing, direct payments, and services contracted through a service provider. For the purpose of this manual information is provided, in general, for an individual who receives their services through a service provider. We will however discuss the Direct Payments model in Section 6. Whatever model of PAS we have it is important that we chose what assistance we need in our lives and our service provider supports us to achieve that. These needs will change over the course of our lives and the PAS should be flexible enough to adapt to our changing requirements.

## Exercise 2: A Review of PAS



**Read the following questions and consider your answers:**

**1. A Personal Assistant is (tick your answer):**

- Someone employed to care for me
- A person who provides me with assistance with household tasks
- A person employed to provide me with the tasks that I cannot do both inside and outside of my home.

**2. I am a Leader because:**

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**3. In Ireland the money used to fund PAS comes from:**

- The Department of Health
- The Department of Social Welfare
- The Department of Justice

**4. Ireland is divided into how many Community Healthcare Organisations:**

- 7
- 9
- 12

## Section 3

# Your Role as a Leader

## Your Role as a Leader

***As a Leader you are the person in control of the service you are getting from your PA. To get the most from your service remember that it is a two-way relationship that requires dual respect and responsibility.***

**Leading your own PAS is a complex role that requires recognition of the complex relationship that exists between a Leader and a PA. A good PAS relies on a positive working relationship developing between our PA and us. It is a complex relationship that can involve many different roles and feelings. We spend many hours in our PA's company and they assist us in many intimate and confidential aspects of our lives. What complicates the relationship further is that one party is being paid to provide a service and therefore there are also obligations placed upon us from a legislative and health and safety perspective.**

### Your Responsibilities

As a Leader of your PAS it is important that you:

- Understand what it means to engage in Independent Living.
- Direct your PAs so that you are empowered to become more independent.
- Behave at all times in a way that acknowledges the dignity of, and shows respect for, the person working as your PA.
- Ensure your PA has a clear job description and that you are both familiar with it.
- Do not expect your PA to take on unreasonable tasks outside of his/her job description.
- Provide your PA with a clear understanding regarding the amount of direction that will be needed in the working relationship.
- Supervise your PA and communicate openly with him/her.
- Adhere to relevant employment legislation.
- Ensure the health and safety of your PA in their working environment.
- Ensure records are kept where required e.g. timesheets etc.
- Remember that your PA is employed to carry out tasks for you. Although friendships can develop they are there to work.

### Induction

Although the PAS has been in existence for decades there are no clearly defined rules or roles for each service. Each PA/Leader relationship is unique and depending upon the PA there may be different ways of organizing the same service. To ensure both you and your PA receive maximum benefit from the service a period of induction training should always be undertaken. During this time you can get to know more about each other, set boundaries, and agree the most important areas of work for your PA to prioritise.

Things to consider during this induction period may include:

- Can my previous PA do a handover to my new PA?
- What tasks do I really need assistance with?
- Do I like the tasks done at a specific time?
- How long do I feel each task should take?
- When will breaks be provided?
- Am I happy to delegate the tasks to my PA to allow him/her the freedom to carry them out to their best ability or do I like to supervise?
- Are there certain places/things within my home which I do not want my PA to access/touch?
- Do I need help with communication?
- What expenses will my PA incur, when working with me, and how will I reimburse them?
- Will I be reviewing my service on an ongoing basis to allow my PA the opportunity to highlight any problem areas and vice versa?

***"As a Leader I have a voice and I am in control".***

*PAS user, Donegal*

## Obligations of a Leader

There are also certain areas of your service that you should familiarise yourself with prior to your new PA commencing their role. These include:

- You are obliged to provide a safe working environment for your PA at all times.
- Your PA will be given training and a handbook including details of their employment rights, role and responsibilities. You should make yourself familiar with the information in the handbook.
- You are not required to provide meals or refreshments for your PA. If however, you ask your PA to accompany you to a place of entertainment generally it is your responsibility to cover any reasonable expenses.
- Remember that at all times your PA is in their place of work. Therefore they shouldn't drink alcohol while working with you.
- If your PA does not turn up for work and offers no explanation you should inform your service provider immediately.
- Your PA is not required to perform any nursing procedure except under the direct supervision (or training) of the Public Health Nurse.
- Your PA may assist with medication by collecting your prescription from your Doctors/Pharmacy. He/she can assist by opening or reading instruction on the container but is not allowed to directly administer medication. In general any change from this policy will only be allowed where appropriate training has taken place and where your service provider has provided clear instruction.
- You must release your PA from their duties to attend compulsory training as and when required.
- You are responsible for protecting any medication, money, valuables or private papers in a secure place. Any suspected misappropriation of property should be reported to your service provider where applicable or to the relevant authorities.
- Your service provider will clarify how any personal property breakages will be dealt with. However you may be responsible for any damage caused to your personal property by your PA and is so this should be included under your personal insurance.

## Training

A PA needs good training and management to do their job well. As the Leader, you must ensure that they understand how to do their job. Training and managing your PA is a skill that you will need to work at. Where possible you should ensure that:

- You communicate in an open, respectful and professional manner with your PA particularly with regard to giving instruction.
- You engage in Leader training to understand what it means to take on the role in terms of training the PA. Generally your service provider provides such training.
- You provide your PA with direction and support during their training and communicate any shortfalls in their training to your service provider. You should then work together with your service provider to ensure these training shortfalls are addressed.



## Exercise 3: You as a Leader



Look at the following areas and tick whether you feel they are traits of a Leader or not

Trait	Leader	Not a Leader
Inspires enthusiasm		
Inspires fear		
Blames others		
Gives credit		
Knows exactly how things are to be done		
Listens to others		
Develops people		
Communicates their needs		
Commands action		
Isn't afraid to ask for help		

A person's foot in a white sneaker is stepping over a red and white striped pole on a sandy beach. The pole is angled diagonally across the frame. The background is a sandy beach with some faint lines in the sand.

## Section 4

# The Leader / PA / Service Provider Relationship

# The Leader/PA /Service Provider Relationship

*The Leader / PA / service provider relationship is complex and can be further complicated by the introduction of the employer (service provider). It is therefore vital that open communication is encouraged in this tripartite relationship from the outset.*

**Communication is key to the successful functioning of the PAS. Essentially as the line manager of your PA you are responsible for ensuring he/she understands their responsibilities and the amount of direction you wish to provide in relation to tasks to be undertaken. However the service provider, from which you receive your services, is essentially the employer of your PA and therefore you must also be willing and able to communicate freely with them regarding your PAS requirements.**

## The PA / Leader Relationship

Through your lifetime of receiving PAS you will encounter many different types of PAs. Each relationship is unique and will often differ depending upon the PA you work with. There is no perfect way of handling any one experience and it is often dependent upon our own personalities and attitudes towards the service. Some disabled people choose not to become friends with their PAs and treat the relationship strictly in a professional capacity; where one person is contracted to provide a service for the other. Other people may feel more comfortable treating the PA as a co-worker and someone who is working with you. Similarly some people immediately treat their PA as a friend and companion, who is a key part of every aspect of your life. Whatever approach you take it is important to remember that PAS is a unique two-way relationship that must demonstrate mutual respect.

*“My PA is not my carer. She listens to what I need and makes my whole life easier. She has brought normality back into my life and has helped me to be myself again ”.*

*PAS user, Galway*

## Boundaries

Like any relationship the one between you and your PA can be a very complex one. It is often a one-to-one relationship and can become intense and personal. Often our PAs work with us in our private realm - in our homes and with our family or friends. You will need to consider professional boundaries. If both you and your PA understand exactly what your responsibilities are then problems are less likely to materialise.

It is important to remember that however you treat your relationship your PA is primarily your employed assistant. Your PA is not expected to take on unreasonable responsibilities, such as sorting out your health, relationships or emotional problems. Similarly if there are certain parts of your life that you would not like your PA to be part of this should be clearly explained as part of the induction process. For example some people do not want their PA to be present during conversations with close family or friends or they may not want their PA to have any dealings with their finances.

To ensure you keep your relationship as healthy as possible you should try to ensure that both you and your PA have space from each other. Working long hours in such a personal setting can lead to irritation. Where possible you should ensure that you have regular time apart. Employing more than one PA or rotating PAs can help with this. It may also be helpful to provide a separate space for your PA to take his or her breaks during the working day.

If you do find yourself leaning on your PA for emotional support speak to your service provider. There are many different types of services available to you that can help to reduce your isolation and help you regain control over your life. Your wellness is important to the PA/Leader relationship therefore should you require support seek advice from your service provider about how you can access support services. These services can often also aid in empowering you to develop friendships and build links within the community.

## Communication

Good communication is vital to your relationship with your PA. From the outset you should be open and honest and talk freely about any issues that may arise. Discuss your own limitations as part of the induction process (physical, intellectual or mental) particularly if they may cause an issue in terms of communication. You should also be clear about what will not work for you. Go through these issues in detail and look at ways in which you can work with your PA to overcome them to improve communication between you.

If you are new to PAS it is understandable that you may have a fear of losing control over certain aspects of your life. You must remember that you are essentially the Line Manager of your PA and to ensure the service works efficiently you need to be able to communicate with each other. Clearly express what your expectations are for the service and the amount of direction you wish to provide in relation to the work that has to be carried out.

## Providing Instructions

Although your PA will have been provided with a job description it is important that you provide clear instructions as to how you expect them to carry out their tasks. Don't just assume that because your PA has previous experience that they will know how to carry out tasks the way you want them achieved. You should be clear in your opinions – be assertive but also mindful of any suggestions your PA may have. It is also important that you do not micromanage every aspect of your service; your PA is at work and should also have some independence over how they carry out their tasks.

## Your Home as a Workplace

Wherever your PA provides you with assistance (home, workplace or social environment) are their place of work. Ensure this workplace is clean and safe for your PA to work in. You should also continually ensure that your PA has all the necessary training to assist you safely. If there are any shortfalls in training you should discuss this with both your PA and service provider.

## Your PAS in your Workplace

For many of us the use of PAS as a workplace support is as essential to successful employment as these services are for living independently in our homes. Just as the level of PA support varies for us in our homes it will also differ in the work environment. PAS that enable us to do our jobs are not necessarily only tasks of a personal nature but may involve services that we require to allow us to complete our job in an efficient and effective manner. Examples of these tasks may include:

- Making and receiving telephone calls
- Dictation
- Photocopying
- Taking notes
- Data entry
- Reading documents
- Organising the workspace
- Travelling to meetings

From the outset it is important to clarify that the PAS you employ in your workspace is different to the services you use elsewhere. You are the employee in your workplace and your PA is there only in a support capacity to you. All tasks that you require assistance with should be clearly explained and at all times your PA works directly to you only. Your PA is not in your workspace to contribute or provide any support to other employees and s/he remains responsible to you only.

Your employer must provide you with reasonable accommodation to enable you to carry out your role. However, the culture of the organization is extremely important to the success of employing workplace PAS.

Employing workplace PAS supports allows you to complete your job without having to spend enormous amounts of time carrying out tasks that could easily be done by your PA. In doing so PAS becomes a more cost-effective solution for your employer as you can make more productive use of your time. Negative colleague attitudes may be encountered therefore it is important that an inclusive culture is developed from the outset through disability equality training where necessary. Clear communication at all levels is vital and any issues should be addressed in your annual review or sooner if necessary.

### Your PAS in a Hospital Setting

From time to time many of us will require a stay in a hospital setting. Although you may require your PAS during this stay it is important to clarify from the outset if it will be available to you. This can differ between service providers particularly if you require admission for a prolonged time period.

When in a medical setting clarify with your healthcare team that your PA will be providing you with assistance. This can prevent difficulties arising particularly with regard to patient visiting hours as you will require your PA outside of these dedicated times. It is also vital that your PA's role is explained, as they are not responsible for your medical care and as such are not assuming the role of a nurse or health care attendant. Your PA is also not responsible for clarifying your medical history, unless you have requested that they do so, and as such any queries regarding your medical care should be addressed directly to you at all times.

### Review

To ensure your relationship with your PA remains positive you should build in regular reviews of your service. Discuss how your PA is performing and any difficulties that you may have. Give honest feedback, particularly if there is something that your PA is doing that is annoying you or breaching your personal boundaries. Try and be constructive with any criticisms that you may have and listen to any suggestions that your PA may have. Although it can be difficult to receive criticism it is important that you see any criticisms that your PA may have as a good way of discussing the issues that may damage your relationship. Listen and acknowledge what is discussed and look for ways that you can address any issues together to improve your service.

### The Leader/Service Provider Relationship

PAS services typically involve three parties. You as the person directing the day to day operation of your service, your PA who is contracted to provide this service, and your service provider who is your PA's employer and the party ultimately responsible for administering your service. To ensure the efficient running of your service it is important that good communication is maintained between all three parties. Any concerns regarding your PA should be addressed to your service provider. Similarly your service provider should address any questions regarding your service, to you in the first instance, before speaking to your PA. If issues do arise it is important you follow the appropriate service provider guidelines, which should have been clearly explained to you when your first contracted your service.





## Exercise 4: The Power of Words



Look at the following areas and tick whether you feel they are traits of a Leader or not

Trait	Leader	Not a Leader
Disabled person		
Wheelchair bound		
Independent		
Sufferer		
Special Needs		
Able bodied		
Cripple		
Integrated		



## Section 5

# Conflict





# Conflict

*Conflict is a breakdown in communication and relationships. Although conflict typically comes from poor communication it can also arise despite our best efforts to maintain a healthy relationship.*

**People involved in close personal relationships can often find themselves dealing with conflict. The expectations we place on our service, our values, beliefs, and emotions can all lead us to experience difficulties with our PAs. We need to recognize and accept that conflict is inevitable and a natural part of being human, but that how we deal with conflict can either be healthy or unhealthy. To make sure that problems, in a relationship, do not become too big to rescue it is vital that conflict is addressed as soon as it arises.**

Conflict can take many different forms and usually grows over a frustration that develops with a person's actions or behavior over a period of time. Low-level frustration can develop for example over the way in which your PA repeatedly carries out a task. Similarly your PA may become frustrated because of your inability to delegate or their working conditions. To ensure that such frustrations do not develop into a serious issue it is important to address them as soon as possible. This can be done through the review process or by simply talking to your PA. It may also be useful to inform your service provider of these minor difficulties so that a record is available should similar issues arise in the future.

Sometimes however relationships can be seriously damaged. For example if your PA abuses the confidential nature of your relationship. Where trust is broken you may become seriously concerned and in particular worried about how it is going to affect your service. It is important to remember that your service provider is there to support you. Reaching out and talking to someone does not make you less independent. It is an important part of your service, which you should avail of.

## Addressing an Issue with Your PA

We need to recognise what conflict is and have a number of approaches to dealing with it in a clear, healthy, respectful way. One approach that many people take is avoidance: to try and ignore the issue or person you are in conflict with, or to suppress your feeling on the issue. Avoidance or suppression are not long-term approaches for dealing with conflict, especially in a close relationship like the one between you and your PA.

Sometimes conflict can be managed by informal agreed methods between you and your PA or you could also involve an independent person to improve communication and build a healthier relationship. The key to managing the conflict yourself is to agree ways to honestly discuss and communicate issues you may have and to be aware that everyone has needs, values, status and an identity that is important to them.

However, if the conflict you face relates to the quality of your service and is impacting on your life, you need to look at non-formal processes relating to your role as Leader, your PA as an employee, and your service provider as an employer.

## Addressing an Issue with Your PA

If communicating with your PA does not address the issue it is important to speak to your service provider immediately. Your service provider is your PA's employer and therefore has a duty to address any problems that may arise. It may be necessary to place your complaint in writing so that a clear record of the problem is available. The steps they take when dealing with issues that arise will differ depending upon the seriousness of the problem. Most service providers will follow all legislative guidelines but still aim to protect the Independent Living philosophy by involving you in every step of the process. Remember however that each problem will involve a different process and often have a different solution.

Depending upon the nature of the complaint and the subsequent investigation your PA may find that they receive a verbal or written warning. In most situations your service provider will aim to work with both you and your PA to overcome any issues and restore the balance in your service. However if your complaint is of a serious nature, for example abusive behavior and is found to be valid, then they may also face suspension or dismissal. It is very important to note that only your service provider can dismiss your PA. If you find yourself in a situation where you want to dismiss your PA or feel threatened by him/her you can suspend them straight away but you cannot dismiss them. You should then immediately contact your service provider, using any emergency number if out of hours and inform them of your situation.

### **Your PA and Your Family Home**

Many Leaders making the journey into Independent Living will require PAS in their family home. This can provide challenges but should be viewed as an opportunity to reduce family dependence and open up new opportunities for both you and your family members. To prevent family members feeling that they are pushed out or fearful it is important to include them in the induction process and any reviews as necessary.

You must clarify with your family the range of supports that your PA will be providing. S/he is there to provide you with support and should not be viewed as a paid support for your family. You must also explain that you are the person providing your PA with direction and s/he will only take instructions from you. Boundaries should also be established and if there are certain areas of your family home that will be off limits this should be clearly explained from the outset. Remember at all times that your family home is also your PA's workplace and s/he must be treated with dignity and respect by all present during his/her working hours.

### **When your PA has an Issue**

Your PA may also find that they have a grievance with the service they are providing you. This can relate to their working conditions or something more serious such as inappropriate behavior. Your PA will have been provided with an Employee Handbook and should follow the process it recommends.

Often your service provider will aim to ensure that the relationship is healed through communication. However if the grievance is of a serious nature then the formal procedure will be implemented. All stages of this process will be recorded and your service provider will ensure that you have the opportunity to have your say throughout. You will also be able to have the support of a family or friend during any formal discussions.

Whatever the outcome it is important that you approach the process in an open manner and discuss all issues with the aim of protecting the integrity of your service.

***"Although I am friendly with my PA the rules of my service are that I don't treat her as a friend. This can be difficult as I have a great connection with her but it has proven important when we have to discuss the job. I'm lucky really as I have great support from my local CIL".***

*PAS user, Roscommon*



## Exercise 5: Conflict Management



Look at the following and decide which you should do and which you shouldn't in a conflict management situation with your PA.

	Do	Don't
Show concern		
Raise your voice		
Avoid talking		
Avoid eye contact		
Show interest		
Talk		
Cover your ears		
Use humour		
Smile sarcastically		
Yawn		
Make eye contact		
Seek help		
Hide your feelings		
Patience		
Roll your eyes		
Leave the room		

## Section 6

# Direct Payments



## Direct Payments

*Direct Payments is the term used to describe the funding given directly by the State to an individual to purchase the range of supports and services they need to live independently. These purchases may include PAS, aids and equipment, therapies, etc.*

**Empowerment is the central theme at the heart of the PAS model. When we receive services through a service provider we are empowered as consumers of the service to take control of its day-to-day operation to best meet our needs. Direct payments take a further step in this process and places control of the service directly with us; enabling us to build our needs and wants around our own lifestyle. With the Direct Payments model we become both the service provider (employer) and Leader (consumer) of our service and many disabled people who use this model do express greater choice and control over their lives. It is however not for everyone and in countries where Direct Payments is readily available there has not been a complete shift away from the service provider model.**

### The International Experience

When we receive a direct payment we receive the funding directly that would traditionally be given to a service provider to meet our support needs. People who receive such a payment then face a choice as to how they will meet their resource needs while meeting all the legal, financial, HR and other requirements they now face. Such decisions are already given to disabled people both in the UK and internationally where direct payments are already readily available. Sweden remains the gold standard for direct payments, where disabled people are entitled to a direct payment for the purpose of employing a PA without regard to the cost of the service or the means of the service user.

### The Irish Experience

Direct Payments have only been introduced to Ireland over the last eight years. In 2010 four disabled people joined together to form Áiseanna Tacaíochta (ÁT), which became the main organisation facilitating direct payments to disabled people in Ireland. When a Leader joins ÁT they introduce an intermediary (middle person) into their direct payment model.

ÁT then acts on the Leader's behalf to negotiate their personal budget with the HSE. This budget is then transferred to that individual's Service Arrangement (SA). ÁT will support the Leader to establish a company through which the funding and all associated requirements (tax returns, financial accounts, insurance etc) are administered. ÁT will both support and oversee the Leader with these requirements. Through the ÁT approach the Leader will establish a circle of support to ensure they have the skills necessary to run their own company.

People who move to a direct payment often express greater choice and control over their lives through the freedom and level of empowerment it provides. Some also demonstrate greater cost efficiency and an increase in the number of service hours they can contract themselves directly. ÁT itself has demonstrated significant cost savings to the HSE by removing the administration level typically provided by a service provider. Although a progressive step toward direct payments in Ireland the number of people receiving support from ÁT is small. Geographical restrictions also remain in place, which means that if you move from one CHO area to another you must renegotiate your entire individual budget again with the new CHO area.

## The Irish Policy Context

Although the last eight years have brought the option of Direct Payments to Ireland there are still a very limited number of people who have negotiated directly a package with the HSE to receive funding for their services. Overall however there is a movement toward individualised supports for disabled people in Ireland. Through the Value for Money report and the establishment of the Task Force on Personalised Budgets the government are now looking at ways in which they can provide us with more choice and control over the services we access to meet our needs.

*"Towards Personalised Budgets for People with a Disability in Ireland: Report of the Task Force on Personalised Budgets"* was published in June 2018. The taskforce has identified three possible forms of personalised budget:

- **Person Managed Fund:** Under this payment option, funds are transferred periodically to a dedicated bank account under our direct control. We may then decide to become an employer and employ our own PAs directly or enter into a contract with a service provider. We then arrange for payments to be made to service providers or staff, etc. in accordance with our agreed personal support and spending plans. With this model we are fully responsible for managing the account, paying for services, keeping appropriate financial records and submitting these to the HSE at agreed intervals. This obviously places significant legal and financial responsibilities upon us, which will require substantial support and training. However we may also decide to contract a third party to ease the administrative burden.
- **Direct Payment to Service Provider:** Under the second payment option our funding is paid directly to a service provider. The contract for our agreed services will remain between the HSE and our service provider but with us determining our services. With this model we select our service provider from a HSE pre-approved list.

We then agree our Personal Support Plan and budget with our service provider, with support from the HSE. Once the terms are finalised we sign a contract with both our service provider and the HSE. Under this model we will be required to undertake mandatory HSE training modules and will also be responsible for any overheads incurred by the service provider (e.g. administrative and operational costs, for example). However it removes the responsibility of becoming an employer or the additional responsibility of entering into an individual contract with a service provider.

- **Broker Managed Fund:** Under the third payment option we engage the services of a suitably qualified brokerage company. Once we receive the list of HSE approved brokers we can choose the one who best meets our needs. The broker may then become the direct employer of our PA, a facilitator of our service, or a manager of our service. We choose and agree the terms and conditions directly with the broker. We will then need to undergo appropriate HSE approved training.

## The Future

The Taskforce on Personalised Budgets recommends developing a number of pilots, over two years, to test the delivery of the personal budget models outlined above. The pilots will test a range of issues such as the cost of operating a personalised budget, quality assurance, employee management issues, governance, and finances. Once these pilots have been completed they will then aim to identify the best approach to a wider roll-out of these payment models into the future.

## Exercise 6: Direct Payments



Read the following questions and select the correct answer (there may be more than one):

**1. The central theme of PAS is:**

- Empowerment
- Control
- Care

**2. Which of the following are part of the Direct Payments process?**

- Knowing the amount of money in your budget
- Developing your Personal Support Plan
- Contracting your services e.g. PAS, physio etc
- Managing your Plan
- Monitoring and reviewing your service

**3. The committee established for examining how the government can provide us with more choice and control of our services is called?**

- The Direct Payments Taskforce
- The Value for Money Committee
- The Taskforce on Personalised Budgets

**4. With the Person Managed Fund approach to personalised budget:**

- I receive my funding directly
- My service provider receives my funding directly
- A broker takes control of my funding

## Section 7

# Conclusions



## Conclusions

***As consumers we know what we need from our PAS. To live our lives to the full we need a range of supports to participate fully in society. We have the control.***

**Much has been achieved in the twenty-six years since Independent Living was introduced to Ireland. We have evolved from an overly medical approach to disability to a model where disabled people are viewed as active contributing members of society. The availability of PAS and its ability to empower our lives has been a primary factor in the growth of Independent Living. As we learn more about our abilities and ourselves PAS becomes more about what we can achieve and less about the provision of care.**

PAS are not without their difficulties and are highly dependent on the unique relationship that exists between our PAs and us. As a manager of our service we need to recognize our responsibilities to both our PAs and service provider. This can be complicated by the complexity and emotions that arise when working in close contact with an individual on a daily basis. No two Leader/PA relationships are the same and there is no one size-fits-all approach to a PAS. Therefore each relationship should be entered into afresh with a renewed approach to ensuring your service improves your quality of life. Respect that unique relationship and recognize the trust and mutual understanding that needs to develop between you. Open communication is vital to maintaining a long-term positive relationship and you should work to develop this from your induction phase.

***"I worry everyday about my PA leaving me. PAs need to be given better wages, job security, and a way to progress if we are to keep attracting the right people. It is a special type of person who will take this job on now and stay for the long-term and that needs to be recognised".***

*PAS user, Waterford*

When you do experience difficulty in your service remember that your service provider is there to support you. Often when we encounter conflict simply improving communication can help but sometimes we may need to recognize that we require help to maintain our service. Seeking assistance does not in anyway diminish our independence and is simply an additional support that we can use as part of our PAS. There are three parties in our PAS relationship and understanding where our role as line manager ends and our service provider's role as an employer begins is an important part in an effective PAS service.

Although we have witnessed a movement away from the provision of care approach to disability, independent living is not without its limitations. The focus on regulations is causing concern that we are moving backwards to a care model where simply providing us with the ability to get 'up, washed, and dressed' is enough to allow us to live independently. An over-emphasis on time management, lack of social hours, and lack of out-of-hours services are all stated as contributing to the isolation of disabled people and a backward step towards the care approach as opposed to true PAS.

Long-term to ensure the sustainability and growth of PAS we need to put ourselves back in control. PAS reduces our dependence and puts us in control of our own lives. By becoming independent we have the opportunity to reduce the dependence we can place on family and friends and instead focus on how we can contribute to society. We shouldn't fear PAS but instead should embrace the opportunities it can provide to change our lives. There is a model of PAS that is right for everyone (direct-payment, self-directing, service provider etc.) what is important is how we manage that service to meet our needs.

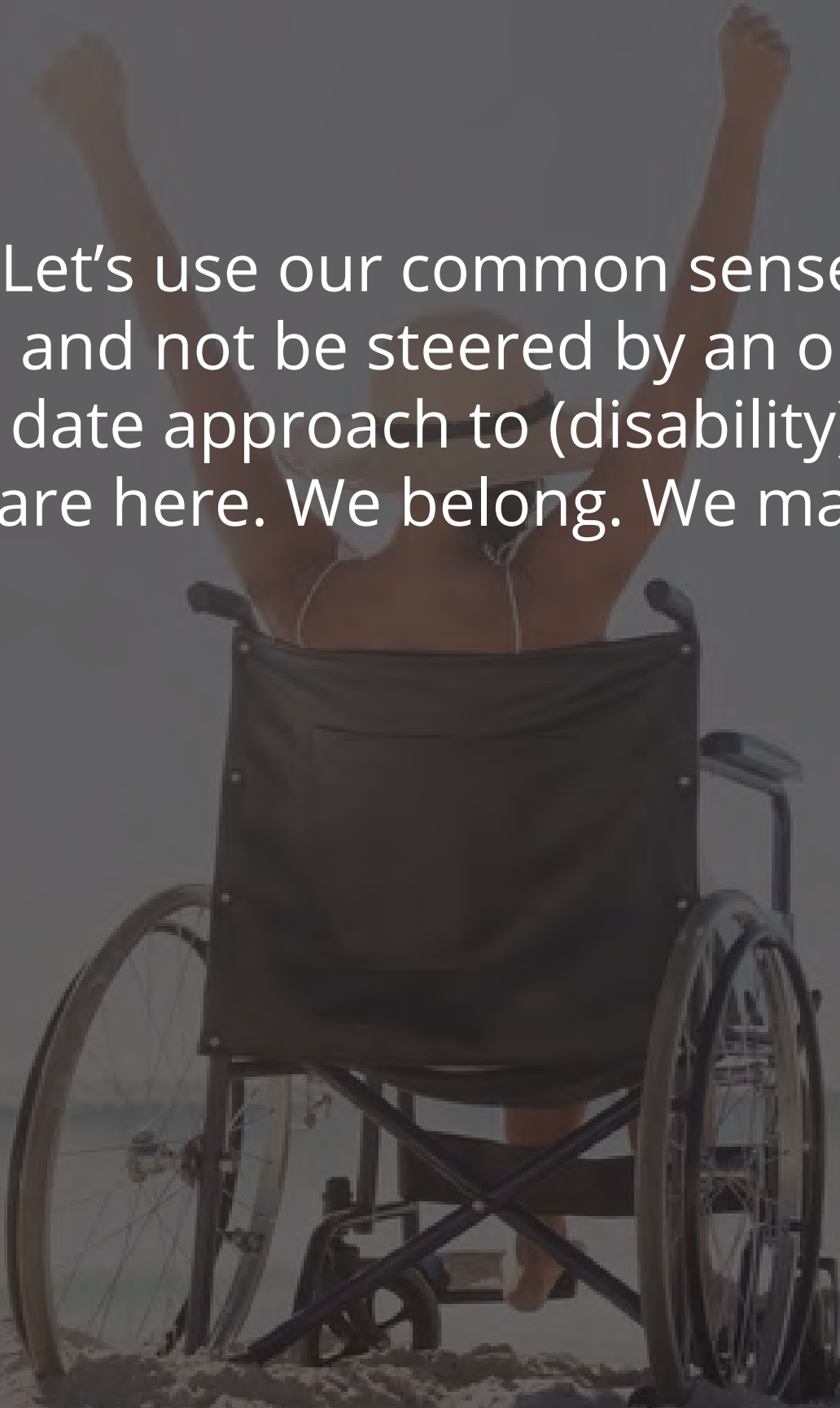
***"PAS is seen as a privilege when it should be recognized as a basic human right".***

*PAS user, Offaly*

## Section 8

# Appendices

“Let’s use our common sense here and not be steered by an out of date approach to (disability). We are here. We belong. We matter”.



# Appendices

## Abbreviations

**ILMI** - *Independent Living Movement Ireland*

**CIL** - *Center for Independent Living*

**PA** - *Personal Assistant*

**PAS** - *Personal Assistance Service*

**HSE** - *Health Service Executive*

**CHO** - *Community Healthcare Organisation*

**ÁT** - *Áiseanna Tacaíochta*

## Further Reading

There are many different resources available should you wish to examine any of the topics in more detail. Some of our general recommended readings include:

- Buchanan, Lillian (2014) Access to Life: Personal Assistant Services in Ireland and Independent Living by People with Physical and Sensory Disabilities: Disability Federation of Ireland
- Cork Centre for Independent Living (2004) Provision of Workplace-based PAs for People with Physical Disabilities, Cork: Cork CIL
- Egan, David (2010) 2Go Direct; The experience of two people using a direct payment to employ a Personal Assistant, Cavan and Dublin: Breffini Integrated Ltd and Center for Independent Living
- Fleming, Pádraic (2016), How Personal Budgets are Working in Ireland: Mental Health and Social Research Unit, Maynooth University
- Keogh, Sinead Dr. and Quinn, Gerard Prof. (2018) 'Independent Living: An Evaluation of the Áiseanna Tacaíochta model of Direct Payments'
- McGettrick, Grainne (1994) Nothing About Us Without Us: Evaluation of the INCARE Personal Assistance Service Programme, Dublin: Centre for Independent Living
- Murphy, Niamh and Conroy, Pauline (2006) Extending the Boundaries: Our Experience of Independent Living, Dublin: Center for Independent Living

## Specific reports and policy papers that you may also find interesting include:

- Department of Health (2013) Value for Money and Policy Review of Disability Services in Ireland: National Implementation Framework
- Department of Justice and Equality (2013) National Disability Strategy Implementation Plan
- National Disability Authority (2017) Report on the Personalised Budgets Consultation Process: ACE Communication Ireland
- Department of Health (2018) Towards Personalised Budgets for People with a Disability in Ireland: Report of the Task Force on Personalised Budgets







Nothing about us without us

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