

Pathways to a Personal Assistance Service (PAS)

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INFORMATION For you

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1 INTRODUCTION: What this document is for

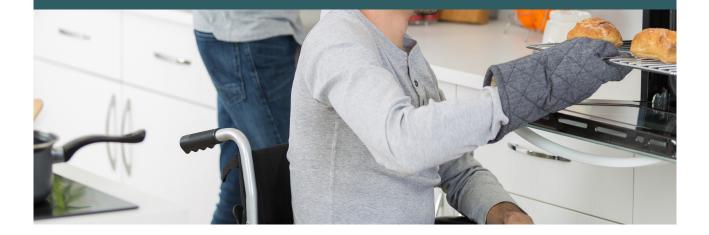


A Personal Assistance Service (PAS) is for any disabled person who feels that they need support to do the things that they want to do, inside and outside the home. Many disabled people do not know about the PAS or what it can do. Some disabled people do not think that they "qualify" for supports based on their impairment.

The process in applying for a PAS can be daunting and complicated. Many disabled people are told that they cannot get the hours that they need or are often told that they need to live independently.

This document is about giving disabled people as much information as possible when they go about thinking of applying for their own PAS.

2 What is a Personal Assistance Service (PAS)?



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With PAS we are in control and direct the PA to carry out tasks both inside and outside of the home, including personal care, domestic duties, assisting in day-to-day tasks such as shopping, support in the workplace or socialising. A PA does not "look after" or "care for" us. We delegate these tasks to our 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.

A PAS is for any disabled person who feels that they need support to do the things that they want to do, inside and outside the home.

3 What could I use a PAS for?

PAS is all about freedom to decide to do the things you want to do. So a PAS is about each disabled person's individual needs. Personal Assistance can be for some, many or all of the following:

'Social Activities' means all activities such as socialising with family, friends and in the community. Personal assistance may include accompanying disabled people while visiting, socialising, and travelling or while on holiday. Assistance can be provided using public and private transport including driving. Assistance can mean different things for different people based on their needs. For example, one person might need physical assistance while another person might need assistance with communication such as interpretation. A PAS can assist a disabled person to develop and maintain social interaction.

'Personal care' involves the following tasks:

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.

PAS can also provide assistance for disabled people in administering medication, communication and interpretation including alternative communication.

'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 and in some cases pets.

In terms of Education and Employment, personal assistance includes assistance in getting to your place of work, education and training, and assistance at such locations. Personal Assistants may be required to assist some disabled people to maintain social interaction within their local community.

4 Learning from other disabled people and building peer support



ILMI recommends that disabled people who are keen to apply for a Personal Assistance Service talk to disabled people currently in receipt of a service. Through one to one individual or group discussions, disabled people can learn more about PAS, including how disabled people currently use it to achieve control over their lives.

ILMI PAS Peer spaces provide an honest space to discuss how liberating PAS can be, but also that having a PAS can be challenging from time to time.

How do I go about identifying my needs for a PAS?



Under section 8 of the Disability Act (2005), every disabled person is entitled to an independent assessment of their needs. As per section 8.5 of the Act, this assessment "shall be carried out without regard to the cost of, or the capacity to provide, any service identified in the assessment as being appropriate to meet the needs of the applicant concerned".

Before applying for a PAS, and having spoken to other disabled people, ILMI recommends that disabled people take time to fill in their own assessment of need. This means thinking about what you would use your PAS for on a day to day basis.

ILMI has developed a template Assessment of Need form that disabled people can use to map out their needs and the amount of hours they think they would need from a PAS to do the things they do. You can list not only the PAS supports you might need but also Assistive Technology (AT) or environmental controls in your home that would maximise your independence and control over your life.

This can be accessed here:

We have also developed a short guide to filling in this form, which can be accessed here:

If you need support in filling in the form, contact the **National Advocacy Service on 0761-07-3000** to arrange local supports.

If you need advice on the process, contact the ILMI peer mentor at **info@ilmi.ie**

b Applying for a PAS

Applying for a PAS can be a complicated process, but here are the basic steps you can take as part of the process.

If you are over 18 and you need a PAS, you need to contact the HSE disability services manager in your Community Healthcare Organisation (CHO) area. Ireland is broken down into nine different areas that manage HSE services locally. Each of these is referred to as a CHO Area.

HSE Community Healthcare Organisation (CHOs)

CHO Area 1-Donegal Sligo / Leitrim / West Cavan; Cavan / Monaghan

CHO Area 2 Galway, Roscommon, Mayo

CHO Area 3 Clare, Limerick, North Tipperary / East Limerick

CHO Area 4 Kerry, Cork

CHO Area 5 South Tipperary, Carlow / Kilkenny, Waterford, Wexford

CHO Area 6 Wicklow, Dun Laoghaire, Dublin South East

CHO Area 7

Kildare / West Wicklow, Dublin West, Dublin South City, Dublin South West

CHO Area 8 Laois / Offaly; Longford / Westmeath; Louth / Meath

CHO Area 9

Dublin North; Dublin North Central; Dublin North West;

The contact details for the CHO Disability Managers (as of March 2022) can be found here:

CH0 1	Edel Quinn	edel.quinn@hse.ie	074 9188 9032
CHO 2	John Fitzmaurice	john.fitzmaurice@hse.ie	093 37932
CHO 3	Maurice Hoare	Maurice.hoare@hse.ie	061 461435
CHO 4	Majella Daly	Majella.Daly@hse.ie	021 492 8754
CHO 5	Anne Ennis	Anne.Ennis@hse.ie	056 778 4319
CHO 6	Patricia McEvoy	patricia.mcevoy@hse.ie	01 274 4205
CH0 7	Deborah Jacob	deborah.jacob2@hse.ie	045 882 582
CHO 8	Jackie Barron (disability manager)	Jackie.barron@hse.ie	041 687 1529
CHO 9	Olive Hanly	headofservicedisability. dncc@hse.ie	01 813 1826

How PAS is delivered and what is the role of the HSE?

How PAS delivered and what is the role of the HSE?

In Ireland the budget allocated to the majority of PAS is administered by the Department of Health through the Health Service Executive (HSE) in the 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.

Disabled people need to demand the type of service that they are provided with. Informed and empowered.

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. However, the process is similar regardless of which CHO area you are living in:

- Contact your Disability Services Manager (details above). Inform them that as a disabled person, you are seeking a PAS to give you control over your life, to do the things you need and want to do.
- The HSE may assign a case manager to directly liaise with you in relation to your needs. They may also assign a social worker to you to talk about your needs.
- 3. If you have already done your Independent Assessment of Need, it is about being confident about presenting this as what your real needs are.

- 4. An application form will be sent to you. If you need support to fill this in confidentially, make sure you are confident to seek for it. Support can include being confident to independently filling the forms in away from HSE staff, service providers or family members. The National Advocacy Service can provide direct supports to disabled people who need them to fill in forms independently and confidentially.
- 5. Continue to link in with ILMI for peer support during the process.
- 6. At all stages in the process, insist as your legal right that all discussions relating to your application involve you. Under GDPR any discussions via email should always include you to ensure you are fully informed of any decisions relating to your needs.
- 7. If the HSE assign a Public Health Nurse (PHN) or social worker to fill in your assessment, you are entitled to insist on an Occupational therapist's (OT) opinion too. A PHN is a medical professional and often they take a very medicalised approach to disability. In the experience of many disabled people, a PHN will often limit discussions for PAS solely within the home or solely relating to personal care, often assigning the disabled person home help. You can seek supports from ILMI and other organisations to challenge this. You can use the ILMI Independent Assessment of Needs (see below) to support your assessment.

8. If you are already in receipt of HSE-funded day care services, you can seek I supports from Day Service Opportunity Officers to change the type of service you receive including moving from Day Service to a Personal Assistance Service. Their role is to support disabled people to change services under the New Directions Office. Contact details for your Day Service Opportunities Officer can be found here, and they can support unbundling the HSE funding from your day service to a PAS.

Funding for disability services has traditionally been provided in a block grant to a service provider based on the total number of people using the service rather than the actual cost of each person. Unbundling means when the HSE pays for services that disabled people are accessing (such as day services) those hours can be accessed on an individual basis for each disabled person can be separated or "unbundled" from the overall grant paid to their current service provider.

Remember

If you have concerns at any stage in the process, you can contact the confidential recipient who deals with concerns that disabled people may have in relation to HSE funded disability services.

Independent Assessment of Need

Independent Living is:

About having control over your life, to have a family, to get a job, to participate socially and to realise your goals and dreams.

Not about doing things by yourself for yourself nor is it about having to rely on "unpaid support" from family members / friends or partners (unless it is the desire of both parties).

According to the prominent disability activist Judy Heuman, 'Independent Living it is being in control of how things are done", and for many disabled people this can best be achieved by having access to a Personal Assistance Service (PAS) and having access to Assistive Technologies that meets a disabled person's particular needs. Other fundamentals to Independent Living include having access to the built environment, housing, transportation, peer support and accessible information.

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

IL is not just about daily living. It is about self-determination, control, choice and the real freedom to make decisions. IL is about people being empowered to challenge societal barriers to achieving full and equal citizenship.

What is an Independent Assessment of Need (IAN)

An IAN (see - online here) should inform the HSE what the applicant's life is actually like living with no service paid support / a skeleton / ad hoc / traditional support or trying to exist without no service (doing things by yourself). It should be carried out without any reference to funding resources.

ILMI's IAN aims to, assess and identify any / all support needs that enables all disabled people to live good lives, taking into account their authentic wishes and dreams, including all aspects of ordinary living, such as:

personal care	parenthood
home management	hobbies
employment	travel
education	sports
social life	political life

All of the above and other aspects of life relevant to the disabled person looking to identify their support needs should be included in the Self-Assessment. A large part of IAN's is helping disabled people to truly think about what they need rather than "being grateful" for outdated traditional support services. An IAN is a "living document" that will need to be updated over time as each person's needs change over time. In 2016, the Irish government committed to setting up structures that enabled disabled people to receive an individualised budget / direct payment to employ the support they need to live good lives (see - Individualised budgeting for social care services for people with a disability: International approaches and evidence on financial sustainability).

A **personalised budget / direct payment** is an amount of funding which is allocated to an individual by (the HSE) so that the disabled person can make their own arrangements to meet specified support needs, instead of having their needs met directly for them by the State.

The completed IAN will enable the completion of a Statement of Required Services. This statement will detail daily living activities, the amount of required PAS hours, assistive technology requirements (if any), required additional supports (if any) and a risk assessment (danger of none of the required supports).

This document is intended to "capture" the individual's totality of both current and future supports required to enable them to live "great lives".

Contact Information

Name:

Address:

Email:

Phone no:

Nature of Impairment and Background Circumstances:

In this part of the IAN you need to talk about:

who you are as a person

your impairment and how it affects your life

Other things you might say here can include:

Your current living arrangements

Current support if any – paid or unpaid – lived experience of having to rely on family and / or inadequate paid support

What you do during the day

Personal Assistant Needs:

In this part of the IAN you need to talk about the reasons why you need a PAS, your current support needs and the tasks that a PA will support you in carrying out these tasks.

Creating a list is always a good idea - Examples could include

I need support from my PA in the following tasks:

Personal care - toileting, showering, grooming, dressing/undressing, overnight support could include regular turning throughout the night and check oxygen mask is on correctly

Support with collection prescriptions / medication when required

Cooking - preparation of breakfast, lunch and dinner and on occasion support with cooking/baking for family/friends

Support with PEG feeding and looking after PEG open wound

Support with taking medication

Support with oxygen mask and face tube

Basic cleaning - washing dishes, sweeping floors, washing and ironing and other domestic chores

Shopping - groceries, household etc.

Physio/exercise - daily physio routine, exercise bike, swimming, muscle stretching Appointments - travel to and from medical appointment, assistance with transfers onto examination tables

Work related tasks - setting up equipment/meeting room, printing, photocopying, filing, note taking etc.

Support to travel to and from destinations

Support to visit elderly parents

Support to seek suitable employment and / or training courses

support to apply to go on local authority housing list or seek appropriate, accessible housing

Support with using assistive technology

Support in making phone calls / texting / sending and reading emails

Support in using internet banking and paying bills

	9am – 6pm	6pm – 9am
	Travel to workplace	Prepare evening meal, assist with PEG feed
	Setup equipment such as laptop, projector	Shower/personal care tasks
	Printing / photocopying of relevant materials for the day	Cleaning, washing up and other domestic duties
	Lunch break- toileting, take out / get lunch	Travel to art class, creative writing class
	Setup for meetings	Full physio routine, muscle stretching before bed
Example of weekday - Monday to Friday	Assistance in going to canteen / staff room for coffee break	Undressing and getting into bed
	Travel home	Overnight support -regular turning throughout the night, make sure oxygen mask is on face
	Attend weekday medical appointments as required	Get up out of bed and dressing
		Full physio routine including muscle stretching
		Prepare breakfast, assist with PEG feed
		Prepare work bag and lunch

Example I - Breakdown on PA support needs with accompanying times:

	9am – 6pm	6pm – 9am
	Get up out of bed and dressing	Prepare dinner, assist with PEG feeding
	Full physio routine	Shower/personal care
	Prepare breakfast	Full physio routine before bed
Example of weekend day -Saturday &	Shopping	Undressing and getting into bed
Sunday	Prepare lunch, assist with PEG feed	
	Exercise bike / swimming, muscle stretching	Overnight support - regular turning throughout the night - regular checking oxygen mask is on face
	Washing, ironing and other domestic duties	

Example II - Breakdown on PA support needs with accompanying times:

Number of PA hours needed in a given week

Detail of tasks requiring personal assistance	Hours per Week
Showering, grooming and toileting	14
Dressing / undressing	7
Physio / exercise - daily physio routine, swimming, exercise bike, muscle stretching	22
Attendance at medical appointments	2
Work related tasks - travel to and from, setup with equipment, lunch, printing, filing, photocopying, setup / assistance in lecture	35
Domestic duties- washing, cleaning, ironing, shop	10
Cooking - preparation of breakfast, lunch, dinner, snacks - support with PEG feed	15
Overnight support - regular turning throughout the night, check to make sure oxygen mask is on correctly	63
TOTAL	168 Hours

Assistive Technology Requirements

In this part of the IAN you need to talk about your assistive technology needs. Usually disabled people that require Personal Assistance will benefit from assistive technology, e.g. environmental controls.

You may need support from a Peer or an Occupational Therapist to identify technologies that would help you to be more independent in and outside of your home.

Risks of not having access to the appropriate supports:

In this part of the IAN you need to talk about the risks that would be associated with not having access to a Personal Assistant Service.

Health Service Provision or Required Service Provision

In this part of the IAN you need to talk about the health services that you currently use or need to look after your health and wellbeing. This could include attending Pilates classes, hydrotherapy/swimming sessions, regular physiotherapy, speech and language sessions, regular gym sessions, counselling sessions, mindfulness classes, book club attendance etc...

Statement of Required Services

In this part of the IAN you need to talk about the risks that would be associated with not having access to a Personal Assistant Service.

Independent Living Movement Ireland

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