

Many terms are used to describe the concepts and practices behind different supports in Independent Living for people with disabilities. Here, the Áiseanna Tacaíochta (ÁT) team has outlined some of the key terms you will come across in exploring our Direct Payments model.

### What is Independent Living?

Independent Living means that you, as a person with a disability, enjoy the same freedom, dignity and choice as everyone else, and that you are empowered to take charge of your own life, making the decisions which affect you for yourself. This extends to all aspects of your life: at home, at work, and in the community.

Independent Living means that you are entitled to and can access the practical support and assistance which enables you to contribute and participate fully in society, equally to other citizens.

### What is a Personal Assistant?

A Personal Assistant (PA) is employed by a person with a disability to empower them to live with independence. As an employer, your PA provides assistance and takes action according to your personal directions and at your discretion; this enables you

to take full advantage of your life opportunities and experiences, and to pursue your goals and interests. Using our model of Direct Payments, for instance, allows you to recruit and train your own PAs and to fit the service around your life. The role of a PA promotes and strengthens your rights to individual choice, flexibility and Independent Living, empowering you to participate equally and to take control of your own life.

A Personal Assistant does <u>not</u> report a Leader's activities to ÁT or service provider personnel. Nor does a personal assistant write in any ledger or notebook, information about their Leader to be viewed by others unless instructed by the Leader to do so.

The role of a Personal Assistant is very different from a Carer or Care Assistant. While we recognise and respect Carers and the need for them in certain circumstances, it is important that we understand the distinctions separating the different purpose and functions of PA and Carer.

#### What is a Leader?

At ÁT, our members are known as Leaders. A Leader is a person with a disability who employs PAs, either directly or through a service provider. As a Leader, you take charge of your PA service, holding responsibility for its daily management. You give your personal instructions to your PAs, dealing with any actions or outcomes from these yourself, arranging training for your PAs and supervising the service. Being a Leader puts you in control of your services.

# • What is a Direct Payment?

A Direct Payment is a cash payment made directly to an eligible person with a disability to enable them to purchase their own care or support services.

Under our model, as one of our Leaders, you receive a budget allocated to support your service needs from the Health Service Executive (HSE). We then support you to set up your own company so that we can re-route this funding directly to you. This allows you to choose and manage your own services, mainly PA.

In Ireland, there is no legal framework yet in place for Direct Payments. This is why our model involves the establishment of a company in order for you to receive your payment. However, by demonstrating the positive impact of Direct Payments in people's lives, as well as their value for money, we hope to establish a simplified model of Direct Payments for people with disabilities in Irish policy.

### What is individualised funding?

Individualised funding refers to all forms of cash payments which can be made to you to purchase services, regardless of whether these are made through an intermediary or not. Direct Payments are one type of individualised funding.

Individualised funding provides real choice and flexibility by giving you purchasing power over your services. This allows you to identify, buy and direct those services that most strongly meet your personal needs and aspirations. You can choose your support services for yourself, as well as when and how you use them.

# What is self-directed support?

Self-directed support is an approach to funding which grants you a greater influence over the money used for your support. The term covers a wide range of supports which are directed by the person receiving them, both with or without assistance.

This enables you to take as much control as you want over your own budget and services; Direct Payments are one such form of support.

By using self-directed supports, you are empowered as an active citizen in choosing how to spend your allocated individual budget and deciding on the support which best meets your needs and goals. Self-directed support allows you to select how your support is provided, ensuring that it fits most closely with your own circumstances and ambitions.

The importance of self-directed support goes beyond its budgeting aspect, and lies in how it enables you to gain control and lead an independent life. Recognising that you and your family are the experts in your support needs, it allows you to live an ordinary life with freedom and choice, and to share in community life, equal to everyone else.

### What is self-determination?

Self-determination refers to your right to make choices and decisions for yourself, reflecting your own needs, ambitions and preferences. Living with self-determination gives you more freedom and independence, as you take control of your own personal activities, make choices for your own education, employment and support services, and develop your knowledge and information. It involves you setting goals for yourself, as well as managing and monitoring your actions in working to achieve them.

Self-determination sees you become an active participant in community life, and is an important aspect of Independent Living for people with disabilities.

# • What is personalisation of services?

Personalisation of services recognizes that everyone should have the choice and opportunity to shape the services that they receive, ensuring that these supports fit with their lives in the best possible way. The aim of personalisation is to tailor services to your needs and to make them more personal. It moves you to the centre of the process, allowing you to become actively involved: this means choosing the ways in which your supports are delivered. Personalisation therefore offers flexibility in responding to your needs, and empowers you to live with input and choice.

## What does it mean to unbundle money?

Unbundling money occurs when a service provider rearranges funding so that you can begin to personalise your supports.

Service providers currently receive block funding from the HSE for the provision of supports and services to people with disabilities. Unbundling money means that the service provider separates the money for your individual service needs from this main block. This money is then exclusively used for your customised support arrangements, although, in many cases, the cost of administration to the service provider may be removed from that amount.

Unbundling money hands you more choice and control. You can either receive this money directly, or work with the service provider to manage how it is spent; the amount of choice and control you have over the funding therefore rests on which of these routes you take.

Under our model of Direct Payments, you receive your money directly, using it to choose and manage your own services. Our model removes the cost of administration fees, giving you greater value for money and more flexibility. Using

Direct Payments to customise your services enables you to actively participate in and contribute to your community.

### • What is an intermediary?

An intermediary acts as a link between people or organisations in order to help the different sides to reach an agreement together. The intermediary's role is to connect the interested parties, present their situations and objectives, encourage discussion, and ensure co-operation throughout the process. The role can involve linking people or organisations who hold funding with those who wish to use that money.

We act as an intermediary between you and the HSE in order to set up a Direct Payment to you. At the moment in Ireland, Direct Payments stand as a new approach and are not set in law; an intermediary is therefore required to facilitate the process.

## • What is brokerage?

A broker is a person or organisation which arranges a transaction between you, the buyer, and a seller, and which takes a commission when the deal is made. This commission, called a brokerage fee, covers services such as negotiations, purchases or advice on the transaction.

In one sense, ÁT acts as a broker: through our intermediary role between you and the HSE, we arrange the transaction which allows you to receive a Direct Payment. As a Leader, you therefore pay a small membership rate to us as a form of brokerage fee. This covers the costs involved in this intermediary role, as well as those incurred in supporting you with the establishment and maintenance of your company.

However, our role stretches far beyond that of the traditional broker. As well as the initial arrangement of these deals - which is where a broker's function normally ends – we work hard to offer you support at every stage, ensuring that the services you receive are continually upheld and monitored to a high standard. We provide leadership and training, encouraging peer support and developing strong networks across communities which you can always turn to for further advice and assistance. We also contribute to on-going research and evaluation which progresses disability policy and leads to the development of alternative supports, including Direct Payments.