Self-directed support

Headway's publications are all available to freely download from the information library on the charity's website, while individuals and families can request hard copies of the booklets via the helpline.

Please help us to continue to provide free information to people affected by brain injury by making a donation at www.headway.org.uk/donate. Thank you.

Introduction

This factsheet is intended for anyone who is currently receiving help from social services, or who may require social support in the future. The factsheet explains how self-directed support operates and how you can make sure you get the help and support you need.

Local authorities have changed how they offer support to adults. In the past, if you were assessed as needing help, local authorities would offer you a programme of services, but under the self-directed support scheme, you will be offered money to choose and fund your own services. This is called a ‘personal budget’. This factsheet explains how it operates.

It is important to note that brain injury can cause people to lack self-awareness and understanding of their own needs. For this reason it is important that help is sought from others when applying for self-directed support. Friends and family can help and so can many of Headway’s Groups and Branches. Details of how to contact these and other sources of support are included at the end of this factsheet.

What is self-directed support?

Self-directed support is about giving people control of the support they receive and the life they lead. It may be referred to as ‘personalisation’ or ‘personal budgets’, but whatever name is given to the scheme the important thing to remember is that it is intended to empower and enable individuals.

Self-directed support is a relatively new scheme which has been introduced across the United Kingdom. Anyone who is currently receiving support from social services, or may be eligible to do so, will be entitled to apply for care under the new scheme. You do not have to use this system if you don’t want to and social services can still be fully involved in planning and delivering your support. However, self-directed support does offer many advantages over the old system. If you are not receiving help at the moment, you can apply at any time to your local social services department.
The scheme will operate slightly differently in different areas depending on how each local authority implements it, but this factsheet provides a general overview of how it works in most places.

**How can you self-direct your care and support?**

There are a number of ways this can be done:

**A personal budget** – This refers to money allocated to an individual by the local authority in order to fund their assessed care and support needs.

**An individual budget** – This combines resources from different funding areas as well as social care funding, such as health care, the Independent Living Fund or Supporting People funding.

**A direct payment** – This refers to payments made directly to you so you can arrange your own support. They can be in regular instalments or one-off payments.

**A personal health budget** – This is an allocation of resources made to a person with an established health need (or their immediate representative). They are relatively new and are currently being rolled out nationwide following a pilot scheme.

**How to get self-directed support**

**First steps**
To apply for self-directed support, contact your local social services and ask for an assessment. You may be asked some initial questions about your circumstances. This is because social services need to decide whether you are eligible before they can offer you an assessment. Generally, people with disabilities or older people are considered to be eligible for an assessment. If you are already receiving help from social services and would like to change to self-directed support you should speak to your social worker about this.

**Self-assessment**
The next stage is completing a self-assessment form to explain what support you need. You can ask for help with filling in the form from a social worker who knows about brain injury, family, friends, or someone who supports you at Headway.

Social services must make the form available in an accessible format, for example in large print or electronically. Some local authorities offer forms that can be completed over the internet.
There is no standard form, but most ask questions which cover:

- Meeting personal care needs – looking after yourself: for example, eating, washing, dressing, shopping
- Relationships – family, friends, people you know
- Being part of the community – for example, using local shops, the library, clubs, community centre, church or other place of worship, helping neighbours, being involved in local organisations
- Work, leisure and learning – having a job, learning new things and enjoying life
- Making decisions – who decides important things like where you live, who supports you, who looks after your money
- Staying safe from harm – for example, when you’re going out on a bus, using a gas cooker, or going down stairs
- Complex needs and risks – can your behaviour be dangerous for you or other people?
- Family carer – if someone in your family supports you, what effect does supporting you have on them?

Under each category you will be asked to tick a box to say whether it applies to you and then explain what your difficulties are. It is very important to give as much information as possible when completing the form as social services will use this information to estimate how much money will be allocated to pay for your support.

Self-directed support money can also be used to help prevent future difficulties. It is important to think about whether you might experience problems in the future if you don’t get help now. For example, you may be a very sociable person and you may feel that without meeting people regularly or attending a support group you could become isolated. Therefore, it is very important that you consider your future needs and make sure that you convey them on the self-assessment form.

The form usually ends with a section for you to make additional comments. Use this section to tell social services anything else about your support needs that you have not included already. It is important to consider all aspects of the physical, emotional, behavioural and cognitive effects of your brain injury when filling in this section. Don’t assume that social services will automatically consider these things as they may not have an understanding of the effects of brain injury.

When you have completed the form you just need to send it back to social services. If you don’t know where to address the form then contact social services or speak to your social worker to ask.
Deciding how much your budget will be

Social services use your form to decide your level of need and estimate how much money you need for your support. They also take into account how much money the local authority has available for care services.

Social services will contact you to let you know how much your budget will be. This is the money (personal budget) that you will have to buy services, adaptations, support or equipment to meet your needs.

Making a support plan

Once you have been told how much money you can have you need to make a plan indicating how you intend to use the money to pay for your support. The support plan does not need to be complicated. It can be as detailed or as simple as you like as long as it covers all the important elements (see below). You may find it useful to ask for help from a social worker who knows about brain injury and family members, friends and your local Headway Group or Branch may also help.

Your plan must cover each of the elements explained below, otherwise social services will ask for more information. You can give your support plan to social services in any format, such as in writing, by email, by audio recording, over the telephone or in person. Remember, it is important to keep a record of what you have asked for.

Your plan must cover:

What is most important to you
This can be people, places and routines as well as help you need. For example, it may be that visiting relatives or friends, gardening, getting to a regular social or religious activity or attending a Headway group are important to you.

What your goals are and what you want to achieve
The plan should indicate what changes you want to make, what you want to achieve and what you need to make it happen. These goals can include anything at all as long as they are realistic and achievable.

How you will be supported
Tell social services what kind of support you want, when you will need that help, how you want it provided and by whom. You also need to explain how you would cope with possible problems. For example, if a family member normally takes you shopping, who will do this when they are away?
How you will spend your personal budget
You need to explain how you will use your budget to pay for this support. For example you might choose to use some to pay for a personal assistant to help with personal care and some for a computer.

You will be able to decide which services, adaptations, equipment or support you want that best meets your needs and your goals. You can ask for anything at all as long as you can justify it and explain how it will be used. For example, you may decide that you need:

- Services such as those provided by a Headway group
- Personal assistants/carers to help with washing and dressing, cleaning, shopping, travelling or participating in leisure activities
- Equipment such as communication/mobility aids
- Memory aids such as pagers and personal digital assistants (PDAs), smart phones, tablets or laptop computers
- Alterations to your home
- Money for transport or to reimburse relatives who regularly drive you
- Holidays
- Anything you think would help meet your needs

How you would like the money to be paid
You also need to explain how you want the money to be paid. You can choose any or all of the following:

- **As a direct payment** to you – usually paid in monthly instalments or as one-off payments, direct payments are a good option if you want to be responsible for managing and spending the money yourself.
- **As an indirect payment** – to a relative or other person known to you, a good option if you do not want the responsibility of handling the money yourself.
- **As an indirect payment to a trust** – where three or more people set up a trust to manage your money for you. For example, three relatives might share the job of managing the money.
- **As a care managed package** – where social services look after the money for you
- **As an individual service fund** – where a sum of money is managed by a service provider on behalf of an individual. The money is restricted for use on providing care and support services for that individual which meet the criteria set out in their support plan. It can include services purchased from other providers.
- **As a broker managed fund** – where you use a brokerage service to manage the money for you (see below for more information on this).
How your support will be managed
You need to explain how your support will be organised day-to-day and how the money will be managed. For example, you may organise the care yourself or someone else might arrange this for you. If you are going to employ a personal assistant or carer, social services need to know that you understand your responsibilities as an employer. Social services will inform you who can advise and support you with this.

How you will stay in control of your life
Social services want to make sure that you are making the decisions about your support. Use this section to explain that the decisions are yours. If others help you, explain how they involve you with decisions. Also say when you would like your support reviewed.

What you are going to do to make the plan work
This is an action plan where you set out what will happen and when. For example, if you have asked for money for a computer and software, you could say when and where you are going to buy it and how you will learn to use it. Social services need to make sure that you have thought through the practicalities of getting and using the support you ask for.

Getting the plan agreed
If your social worker is happy that your plan will meet your needs and that you can get what you have asked for within your budget, they will agree it and sign it. If they need any more information from you to make their decision, they will contact you.

Organising the money
Once your plan is agreed, social services will arrange for the money to be paid, either to you or to whomever you said in your plan will manage the money for you. See the section above on ‘How you will spend your personal budget’ for more information on this.

Organising the support
The person who receives the money is then responsible for organising the help needed. This may be buying equipment, employing a carer or personal assistant, arranging trips or any other help and assistance you need.

Social Services will put you (or the person receiving the money on your behalf) in touch with local voluntary and community organisations who can advise on anything related to organising the support. For example, advice on employment issues, insurance or taxes or more general support if needed.
Will you have to make a contribution?

You may be asked to make a contribution towards your budget depending on your savings and income. You will be asked to complete a form explaining how much money you have saved and what your income is from earnings, benefits, pensions and investments (sometimes called a ‘means test’).

Brokerage

Brokerage services are independent organisations that help you to find and organise the support you need. A brokerage service may also help you manage your individual budget, find carers, personal assistants and support groups, and help you with your duties as an employer such as employment contracts and tax and National Insurance contributions. There is normally a charge for brokerage services but this should be built into your individual budget.

The availability and type of brokerage services varies across the UK. Your social services department or social worker will be able to provide you with details of local services.

Monitoring and review

You can ask for your self-directed support package to be reviewed at any time. A review should be carried out at least once a year and social services will normally contact you to arrange this. If you have not heard from them or you would like a review sooner, you can contact social services yourself to request this.

The review should cover how the help is working, consider any difficulties that have arisen and any extra help or changes you would like. You can also use the review to think about and plan for future needs.

Can my carer still receive support?

Yes. A carer who provides assistance to you is entitled to a carer’s assessment. Some local authorities include the carer’s assessment as part of the self-assessment form. You would complete the form together and return it to social services. However, some carers may want a separate assessment, often due to pressure they feel from caring. If so, your carer is entitled to his/her own assessment and should ask social services for an assessment which may reveal that he/she is also entitled to a personal budget.
What to do if you disagree with a decision

If you are unhappy with the decisions that social services make at any stage of the process you have a right to challenge the decision. For example, you might be unhappy that they:

- Did not allow you to fill in the self-assessment form because they did not believe you will be eligible for help; or
- Had too much influence and you did not have enough choice; or
- Will not sign off your support plan even though you feel it meets the outcomes you want and addresses all necessary points; or
- Are not giving you enough money to get the support you need.

If you are unhappy with a decision, you can ask social services to look at their decision again informally to see if they will change their mind. If this does not change the decision or you want to challenge the decision more formally you can make a complaint.

Complaining to social services is now just a one-stage process and is geared towards resolving the problem rather than just responding to it. Contact your local authority for details of their complaints procedure, or contact the Headway helpline for more information and to discuss your situation.

Your local Headway Group or Branch and your Headway regional co-ordinator may be able to support you to contest a decision. Please contact the Headway helpline to discuss this.
Sources of further help

Further information about brain injury, including useful publications and details of local Groups and Branches, is available on Headway’s website at www.headway.org.uk.

For further information about self-directed support, contact In Control. This is a national charity set up to assist local authorities in delivering personalisation. Their website contains a range of information about self-directed support, including a number of freely downloadable factsheets. Visit www.in-control.org.uk or contact them on 01564 821 650.

For information specific to self-directed support in Scotland, visit the Scottish Government’s self-directed support website at www.selfdirectedsupportscotland.org.uk.

To discuss any issues raised in this factsheet, or to find details of our local groups and branches, please contact the Headway helpline free of charge on 0808 800 2244 (Monday - Friday, 9am-5pm) or by email at helpline@headway.org.uk.

You can also find more information and contact details of groups and branches on our website at www.headway.org.uk/supporting-you.