Self Directed Support:

my support, my choice: your guide to social care

Contents

Introduction	page 1
Getting Support	page 2
Assessment	page 7
The Money	page 12
Choosing from the 4 options	page 14
Option 1:	page 16
Option 2:	page 22
Option 3:	page 25
Option 4:	page 27
Planning your support	page 29
Reviewing your support	page 31
What if things go wrong?	page 32
Your human rights	page 34
Support and information	page 35
Appendix: Jargon Buster	

Introduction

Who is this guide for?

This guide can help you if you are getting social care support or if you are thinking of getting support.

This may be because you are a disabled person or because you have other support needs, like a mental health problem. Or it might be because you are an older person who could use some extra support to keep your independence.

This guide will also be useful if you are a relative or friend of someone who has support needs. If you are a carer you will also want to read another guide in this series - "Self Directed Support: a carers guide".

If you work with people who have support needs you might also find this guide helpful. However you will also want to read "Self Directed Support: practitioner guidance".

How to use this guide

This guide contains a lot of information about getting the support that is right for you. It does this by describing the step by step journey from first asking about support to having all your arrangements in place.

If you are seeking support for the first time you might want to read the whole guide. If you already receive support you might only want to read certain sections of the guide.

Getting help from others

Many people find it hard to take in a lot of information on their own. You might find it helpful to read this guide with someone you trust who can offer you support and encouragement as you go through it.

This might be a relative, friend or carer, a practitioner, an advocate or someone you know from a care agency or support organisation.

Getting Support

What is social care support?

If you think you need support in your daily life then you may want to contact your council to talk about this with a professional, like a social worker.

They will work with you to find out what support you might need. If they agree you need support they will arrange it with you.

Social care support is available to everyone, but whether you get support depends on what your needs are and your council's rules.

Why do I need a guide to social care?

Social care is changing. In the past your council would have decided what support you should get and arranged it for you. You wouldn't have had much say in who supported you or the kind of support you got.

Now you can have much more choice over your support. The council should work with you to help you find support that you want and which fits with your life.

This is called Self-directed Support.

What is self-directed support?

Self-directed support is about having choice, control and flexibility over the support you receive.

Self-directed support is when...

- You work with the council to make sure you get support that's right for you.
- You are treated with respect by the professionals working with you.
- You are given help to understand the choices you have and are able decide what choice to make.
- The professional helps you look at **new and different** ways to support you to live life the way you want.
- You are **involved** in deciding how your support is planned and arranged.

- Your support helps you to take part in the life of the community.
- You are given as much control over your support as you want and you use that control responsibly.
- Your support helps you to feel safe and secure but also allows you to take some **risks** that are necessary for you to learn new skills or do new things.

How do I get support?

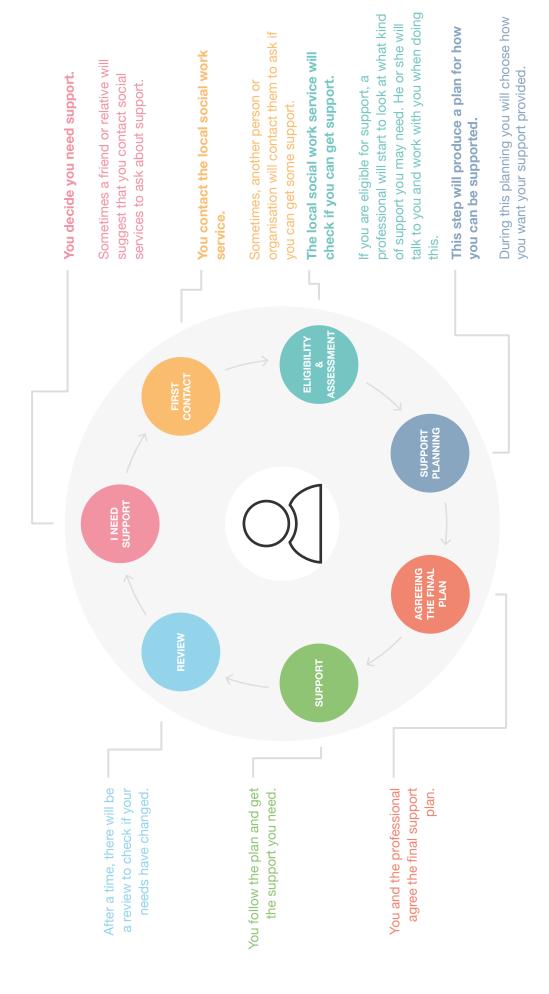
In your area there will be a contact telephone number for your council. You can call yourself, or have a friend, neighbour, doctor, family member, nurse, or someone else make contact for you. Or you can go onto your council's website and search for social care services, social work services or community care services to find out more.

A professional from the council will arrange to visit you. They will start to assess the support you need, and whether the council can give that support. There is more information on assessment in the next chapter.

If you already get support but you don't think it is meeting your needs you can ask for a review.

The Person's Pathway

There are different steps to getting support. The steps are called the Person's Pathway. Here's how it might work for you.



Who might be involved in my support?

You

There is nobody who is more of an expert on your life than you. Your family or friends can also be involved too if you want them to.

The professional working with you

This will usually be a social worker from the council but in some cases it might be another professional, such as an OT (Occupational Therapist), or someone from the National Health Service. Their job is to listen to you and the other people in your life to find out if support would make things better for you.

If support would make things better for you, the professional will work with you to arrange support that is right for you.

Support provider

This is the person or organisation that gives you the support you need. It could be:

- An organisation that provides staff and other support to you
- A personal assistant that you employ to support you
- The council or the NHS
- Or any organisation that provides a service that could help you

Support organisation

This is an organisation or group that can help people with choosing and organising their support. It could be:

- A Centre for Inclusive Living
- A SDS Peer Support Network
- An Independent Broker
- An Advocacy Service

There are lots of support organisations. You can find out what organisations are in your area by using this website: http://www.sdsinfo.org.uk/

Can children get support?

Yes. Like an adult, a child may need support because they have a

disability or another health problem.

A child might also need support because they are at risk in other ways. For example a child might need support if one of their family members has a health problem or an addiction to drugs or alcohol.

If a young person is aged 16-18, then they can choose what kind of support they want.

If a child is aged under 16, then their parent or guardian will make decisions about the child's support but the child must be involved in deciding what happens as much as possible. The local council will give the child information about the different kinds of self-directed support in a way that they will understand.

Most of the information in this guide is useful for children and young people who get support, and their parents. However there is some information which is only useful for children and young people and their parents. This information is indicated by this symbol throughout the quide:



Information and help

Whether you are getting support for the first time or have been getting support for years it's important to know that you can get information and advice at any time.

You can get information and help from a number of different places.

Help from your council

Your council will be an important source of information about your support. The law says your council must give you information about

- all the different kinds of support you can get
- how to manage support
- where else to get information and help.

This information must be in writing. If you need that information to be given to you in another way, such as through an interpreter or in another language, your council must do this for you.

Help from your family and friends

Another important source of information and advice is your friends and family. Your friends and family can have as much say as you want in the decisions you make about your support.

Help from support organisations

Support organisations can offer you help in different ways:

- 1. Information and help from people who have had support from the council because they have an impairment or another support need.
- 2. Support to plan and make your own support arrangements by using direct payments.
- 3. Training to:
 - speak your mind and stand up for yourself
 - manage your support or manage the money for your support
 - employ your own support staff

You can find out what support organisations are in your area by using this website: http://www.sdsinfo.org.uk/

Help from an independent advocate

An independent advocate is a person who could help you to have a stronger voice when speaking with your council. An independent advocate will help you get the information you need to make real choices about your support. They might also speak to the council for you if you cannot.

You have a legal right to independent advocacy if you have:

- dementia
- mental ill health
- a learning disability
- an acquired brain injury

The council must tell people about independent advocacy services and how to get advocacy support if they think the person will benefit from this.

If you want to find an Independent Advocate in your area use this website: http://www.siaa.org.uk/find-advocate/

Your assessment

What is an assessment?

The assessment is one or more talks you have with the professional working with you. During these talks the professional working with you will try to find out:

- what your needs are, and
- what things matter to you in your life.

The professional will also meet with your carer too (if you have one) to find out their views.

What are needs?

The professional working with you must first find out if you have needs. You could have needs for a number of reasons, like being a disabled person, having mental ill health, being an older person, using drugs or alcohol, or being homeless.

Councils do not have to provide support for all needs. The professional working with you must find out if you have enough needs for the council to provide you with a support service. In other words, they need to assess whether you should have their support.

How does the council decide if I should have support?

The council sets its own rules for this. The local council will look at the level of risk to you if you do not get support.

Usually there are 4 kinds of risk:

Critical Risk:	There are lots of risks to your independent living or health if you do not get care and support.
Substantial Risk	There are quite a lot of risks to your independence or health if you do not get care and support.
Moderate Risk:	You may need some care and support now or you may be able to manage by yourself or with some help from family and friends
Low Risk:	You are not likely to need care and support services now but may need some information and advice

Helpful hints

The professional who does the assessment must think about all of your needs and risks. They must also think about

- if your needs and risks will change in future;
- what will happen if no support is given to you;
- if you have any needs that may not be easy to see at first, and;
- what support your carer (if you have one) can or cannot provide.

Once the council decides that a person should have care and support, it cannot refuse to provide support because of money reasons.

The council should make it easy for anyone to get a copy of their rules and understand them.

What if the council decides I don't need support?

If the council decide you don't need support from them that shouldn't be the end of it.

The professional working with you should help you find other places where you can get support. This could be

- Your own skills and strengths
- People you know, such as friends and family
- Other people in your community
- Local charities or support organisations
- Printed information or websites that could help you.

Don't be afraid to ask for more information. You can also contact the council again for another assessment if your needs change.

What if the council decides I do need support?

If you do need support, the professional will work with you to find out more about what you need but they will also want to know what matters in your life.

It is important that you are supported to decide which things matter in your life so that any support you arrange doesn't get in the way of these things. The support you agree with the professional working with you might help you to be able to do more of the things that matter to you.

You should be supported to decide:

what is important to you in your life
why these things are important
how to go about doing or getting these things
who will be involved in your life and support

The thing that matters most to you might be changing the way you feel.

"I feel better about myself so I can get out and about again."

"My health is better so I am as well as I can be."

Or it might be keeping something in your life going even if your circumstances are changing:

"I am able to keep in touch with my nieces even though my health is getting worse."

"I am able to go to keep my job even though I have good days and bad days."

Or maybe the thing that matters most is being involved in making decisions about your support:

"My social worker and my support workers listen to me."

Questions to help you identify what matters to you:

- 1. If you could change your life what would you do first? Then what would you do? And then what?
- 2. What difference would that make to you? To others?
- 3. Where would you be doing this?
- 4. What sorts of things did you used to really enjoy doing?
- 5. What would help you to do these things again?

Helpful hints

The professional working with you might call this finding your 'outcomes'. Your outcomes are the things that matter in your life and the impact your support has on your life.

What will my assessment be like?

Every assessment will be different. An assessment should be all about you and your own circumstances. However to help you know what you should expect from your assessment we've listed the top 7 things that make a good assessment.

A good assessment...

- is a calm and comfortable conversation with a professional
- considers what the whole of your life is like not just the needs arising from your impairment or other condition
- is about your strengths and skills as well as your needs and support
- is not just about ticking-boxes or filling in forms
- is when you and the professional are open and honest with each other.
- is when you are given enough information and advice to fully take part. Including independent information from outside the local authority.
- is when your professional listens to you and encourages you to say what you think.



Children

For children under 16 the parent or guardian will be more involved in the assessment. It is important that the child is as involved as possible in the decisions about his or her support.

During the child's assessment, both the professional and parent or guardian should be thinking about how the support will help the child's wellbeing by keeping him or her: Safe: protected from abuse, neglect or harm

Healthy: having good physical and mental health, and supported

to make healthy safe choices

Achieving: getting support and help in their learning, boosting

their skills, confidence and self-esteem

Nurtured: having a happy, healthy place to live and grow

Active: can take part in a wide range of activities – helping

them to build a fulfilling and happy future

Respected: having a say and being involved in the decisions that

affect their well-being

Responsible: taking part within their schools and communities

Included: getting help and guidance to overcome problems and

to help them be full members of the communities in

which they live and learn

Who can I involve in my assessment?

Your assessment doesn't have to be a talk between you and the professional working with you only. You can involve other people who can help you by giving you information and advice.

Advice and Information

- Remember you can ask you family members or a friend to help you at this stage.
- You can also get support from a local support organisation.
 Find your local support organisation: http://www.sdsinfo.org.uk/
- Could an independent advocate help you to have a stronger voice? Find an advocate in your area: http://www.siaa. org.uk/find-advocate/

The money

Why do I need to know about the money spent on my support?

You might want to take control over the money that is spent on your support so that you can spend it in a way that suits you better.

Before you choose how you want to get your support, the council must tell you the amount of money you can have.

Helpful hints

Think of it this way, you wouldn't go to the shops without knowing how much money you had to spend.

In the same way, your council won't ask you to choose how you want to get your support without telling you how much you have to spend and giving you an idea of what that could buy.

The amount that the council offer you for your support is called your individual budget.

Where does the money that is spent on my support come from?

Usually it will come from the council's social work budget.

This means you and the professional working with you should only spend it on things that are part of your support plan.

How do the council decide how much money I will get to spend on my support?

Different councils will do this in different ways, but they must do certain things:

- Your council should have a way of deciding a budget that is fair and clear to everyone.
- The professional working with you should be able to tell you how much money you can get
- The amount of money spent on your support should be enough to pay for everything in your support plan.

 Before deciding how much money to spend on your support, the council must talk to the professional who has worked with you to agree on the kind of support you need.

What if I don't think I'm getting enough money?

If you disagree with any part of your assessment, including if you don't think you have been given a big enough budget to pay for your support, you should tell the professional who did the assessment.

If you can't agree on any part of your assessment you might wish to make a complaint (see the "What if things go wrong?" section for more information).

Will I be charged for the support I receive?

To receive any support from the council you will usually be means tested. This means that the council will ask for details of your income and savings to see whether you should help to pay for it.

Your council might ask you to pay money towards your support.

Your local authority will ask you to pay the same amount, no matter which option you choose.

Choosing from the 4 options

After you have...

- been assessed as needing support
- had a conversation with your social worker about what matters to you in your life ✓
- had a conversation with your social worker about what kind of support you might want ✓
- been given a budget for your support ✓

...the professional working with you will offer you a choice of options of how you want to get your support.



Children

If a child is aged under 16, then their parent or guardian will make decisions about the child's support.

Children must be involved in deciding what happens as much as possible. The local council must give the child information about the options for self-directed support in a way that they will understand.

What are the four options?

This part of the guide tells you what each of these options are. The professional working with you will tell you more about each of the options and how they apply to you.

"I get the money to spend on support I choose." This is usually called a direct payment. The council pay money directly to you and you arrange your own support by employing care staff or buying services from one or more organisations.

"I tell the council how to spend the money"

The council or an organisation of your choice holds the money but you are in charge of how it is spent.

"I let the council decide how to spend the money"

You ask your council to choose and arrange the support that it thinks is right for you.

"A mix of options 1, 2 and 3"

Option 4 lets you choose a mix of these options for different types of support.

Helpful hints

The law says that the council must give you all the help you need to understand all the choices and to be able to decide what choice to make.

Making decisions

Some people find it hard to make decisions on their own but can do this with some help.

The professional must decide if someone needs some help with making decisions. If they do, the professional must try and find someone who can help the person.

People who can help include friends and relatives or a circle of support.

The supported person must agree that they need and want this extra help with decisions before anyone is asked to help.

Telling others about decisions

Some people find it hard to communicate with others due to a disability or language problem.

They can make decisions but may need some help to tell others. They may need help from an interpreter or a speech therapist or someone they know.

If a supported person needs help to tell others about decisions, the professional must try and find someone who can help the person.

The supported person must agree that they need and want this extra help with decisions before anyone is asked to help.

Advice and Information

- Remember you can ask your family members or a friend to help you at this stage.
- You can also get support from a local support organisation.
 Find your local support organisation: http://www.sdsinfo.org.uk/
- Could an independent advocate help you to have a stronger voice? Find an advocate in your area: http://www.siaa. org.uk/find-advocate/

Option 1

"I get the money to spend on support I choose"

What is option 1?

Option 1 is often called a Direct Payment. It is a payment made to you with which you can buy support. You can do this on your own or you can get help from family, friends and support organisations.

How can it help me?

You might want to take control of the money spent on your support for many reasons. It might be because you find the social care support that is arranged by your council isn't quite right for you. Maybe the support workers come at times that do not suit you or you don't always get the same members of staff.

Another reason might be that you want to pay for something that the council does not normally provide. Or you just might like being in charge of how the money is spent on your support.

What can I use the money for?

You can use it in any way you like as long as you can agree with the professional working with you that the support you buy is the same as what is in your support plan.

Many people use direct payments to employ a carer (called a Personal Assistant) directly. Others use it to buy services from a care provider organisation. Some people use it to take part in hobbies and activities that they enjoy.

Here are some examples of what people spend their direct payments on:

- employing one or more Personal Assistants (PAs)
- buying support from a service provider
- · buying short breaks or respite care
- buying equipment or adaptations to your home

 help to attend activities, education or employment, like going to a social club, college or work

I want to use my direct payment to employ Personal Assistants. What do I need to know?

If you are thinking of using a direct payment to employ a personal assistant (PA) you should read the Personal Assistant Employer's Handbook http://www.scotland.gov.uk/Publications/2014/04/4710.

Employing a PA can give you support that suits you best because you can choose who comes into your home and exactly what they do to support you.

If you choose to employ a PA, there are some things the law says you have to do. For example, when you are interviewing potential staff or setting up payroll arrangements. There is lots of support available to help you do this. You can get support from the professional working with you and local support organisations to help you manage this.

Stuart's Story

My name is Stuart and I live in a small village in the Lothians. I have MS and I have been managing my own Direct Payment for almost 2 years now. I previously received a service from an agency, however, they were going through some changes and unfortunately they had to make some of their workers redundant and this included my regular carer. I was told about Direct Payments by my social worker, and I decided I would go for it, so I could employ my old carer from the agency who I had a good working relationship with. It all seemed a little daunting to begin with, but I had a meeting with my social worker and an Independent Living Officer (ILO) from my local support organisation who explained how the direct payment could be used and what my responsibilities would be if I decided to become an employer of my own Personal Assistants.

My local support organisation supported me to get everything in place before I started to employ my own PA. They helped me get set up with payroll, organise contracts of employment and decide on a suitable rate of pay for my PA. They advised me to make sure I reserved enough funding to cover my costs such as holiday and sick pay, things I never knew I had to consider. Once I got set up, and I used the payroll service a couple of times, I was in full swing of managing my own direct payment. I found a second PA who could

work for me as relief. This meant that I had the security knowing that I had back up if my first PA was ever off sick or needed a holiday. I could also use an agency at the same time to cover any gaps.

Over the last two years I have had to recruit PAs on a couple of occasions. Whenever I need to advertise, I contact the support organisation who organise everything for me. We look at my job description and advert to make sure it covers everything I need. Because I now have a mobility car, I look for people who have a driving license so I can use my PA to go to the shops or visit friends. My ILO takes away all the hassle from recruiting. They keep me right by making sure I keep in line with employment law guidelines. Whenever I have a problem, I know I can just call the support organisation and they will be able to advise me on what to do. Even when it's something I've dealt with before it's always good to know I can just call and reassure myself that what I'm doing is right. I send my timesheets into payroll every month and they do all the calculations for tax, holiday pay, sick pay... everything really. I don't think I would still be managing my direct payment as well as I am if I didn't have this help.

Last year, I received additional funding into my direct payment to use for respite. I had tried traditional respite before, but it just wasn't for me. I used to book in for a week but ended up going back home early so I wasn't getting the full use of it. I was lucky to have an understanding social worker who suggested we apply for my respite as a DP. With getting the respite funding paid into my DP account, it meant I could choose to go somewhere completely different for a break. I decided to rent self-catering accommodation just south of the border. The accommodation was completely accessible and really affordable. My PA came with me for the weekend and I had a lovely break and I really felt like I completely got away from it all.

To me this means I can arrange my to suit my own needs. If I'm not feeling well one day and I need more support I can call my PA and ask them to work a longer shift to give me an extra hand. I also feel in more control of my life – I arrange rotas around my personal life so I can get out to socialise and do the things I want to do when I want to do them.

It's important for me to have staff who I trust and can build a good relationship with and my direct payment has allowed me to achieve this. I couldn't have done it without all the support I have had from

my support organisation. You never feel alone knowing you have an experienced advice service behind you. Having a direct payment has been fantastic for me. I really believe it has given me my independence back.

I want to use my direct payment to buy services. What do I need to know?

You don't have to use your direct payment to employ someone. Many people use a direct payment to buy services from a provider organisation. One of the good things about a direct payment is that the provider organisation works for you, not the council.

Help is available to work out the arrangements. You can work with the professional working with you, your local support organisation and the provider.

John's Story

John is 20 and from birth was diagnosed with a learning disability and epilepsy. From the age of nine John received a service from a provider which was funded by the council's children's services department.

This outreach service supported John and his other family members to participate in events within their own community.

When John moved to the Council's Adult Services department he learned they did not buy outreach support from the provider that had been supporting him. However John and his mother both wanted him to continue using this support.

John's mother took the opportunity to agree a Direct Payment arrangement with the Council and with this she purchased the same outreach support that John had been receiving for years.

This support provided John with much needed continuity with the opportunity to continue participating in activities within his local community. It also allowed that provider to support John's move into adult services because they had worked with him for a long time and knew him well.

The direct payment option gave John and his mother a lot of flexibility in buying services that still met the outcomes set out for John in his care plan.

What will I have to do?

You will need to keep records because the money comes from the council and they will need to know it is being spent on your support. Your council will ask you to set up a separate bank account for the payments to go into and they will ask you to provide regular statements showing how you spent the money.

Will the council check how I spend the money?

Your council will need to be sure that you are getting the support you need. There are different ways of checking this, but the council should tell you how they are going to check how you spend the money.

Who can get and manage the direct payment?

You can get support to manage the payment yourself from a support organisation. If you don't want to manage the payment yourself you can get someone you trust to manage the payment on your behalf, as long as you are still making the decisions on how it is spent. This could be a relative or friend or a provider organisation or someone in the council.

Can I employ a family member?

Yes, but the professional working with you would have to agree it is right that you should employ them. The professional will only agree if he or she thinks that employing a family member will help you to meet your needs.

The professional working with you will not allow the family member to be employed if they think that he or she is forcing you to agree to this arrangement. Nor will they allow the family member to be employed if they are the one managing the payment because they have guardianship or power of attorney.

Can I purchase residential care?

No. Your council will not let you purchase long term residential care – meaning any stay over four weeks. But if your assessment says you need residential care, your council should give you a choice of where you want to stay.

Can the council refuse to give me a direct payment?

Your council might not offer you the option of a direct payment if your safety is at risk for any reason, such as if you need to get away from being abused by a family member.

Otherwise you will be offered option 1. But remember that the council can refuse to give you a direct payment to buy support that you have chosen if they think it will not meet your support needs. For children, the council must be sure that the support bought will protect the welfare of the child before it will agree to it. (See "When can the council refuse my choice of support?").

Is it like a benefit?

No. Usually when you get a benefit it is up to you to spend it as you please. But the money given to you for social care must be spent to help you meet your support needs.

Does it affect my entitlement to benefits?

No. A direct payment will not affect how your income is assessed for benefits or for tax purposes.

"I tell the council how to spend the money"

What is option 2?

Not everyone will want to get a direct payment but many people will still want the freedom to choose who provides their support.

If you choose option 2 you don't have to get any money. The council will pay the money to one or more organisations that you have chosen. This way you have choice and control but won't have to worry about arranging things.

How is option 2 different from option 1?

The main difference from option 1 is that you don't hold the money yourself, but direct the council, or another organisation, as to how it should be spent. This would mean that you don't need to set up a separate bank account or show how the money has been spent. You still have choice over your support provider.

Another big difference from option 1 is that you cannot directly employ a Personal Assistant. You can only do this through option 1.

If I don't hold the money then who does?

Under option 2 either the council or your chosen support organisation will hold the money.

You can talk with the professional working with you about which arrangement would be better for you.

How do I find out who I can buy support from?

The professional working with you will have a list of local providers in your area. Local support organisations may also be able to give you information on other providers, and your professional will be able to signpost you to these.

Some support organisations will have brokers. A broker is a person whose job it is to provide you with advice and information about what providers and types of support are available in your area.

The Care Inspectorate website has information on finding and choosing a service. You can use its Care Service List to find out about support providers in your area and check their ratings.

Remember that you are the customer so feel free to contact more than one provider before deciding which one to use.

What support can I buy?

You should be able to choose any provider or service as long as the professional working with you agrees that they will help you to meet your support needs.

The professional working with you may refuse your choice of provider or service if they think that the support you have chosen will not give you the kind of support that you agreed during your assessment. (see "When can the council refuse my choice?" in the "What if things go wrong" section). You cannot directly employ a Personal Assistant.

Steve's Story

Steve is 32 years old and has autism, learning disabilities. Steve has spent a number of years in a hospital setting due to these difficulties. Steve was very unhappy and often distressed with his situation.

By using an SDS approach he has been supported to successfully return to live in his own flat with support.

Steve, his family and key health staff were involved in the assessment. Steve and his family decided to buy support from a provider using option 2.

The provider involved Steve and his father in the recruitment of a dedicated team to support Steve and work was done to ensure that the right match of workers was found.

Steve has been supported every step of the way to make choices about how he wants to receive his support and regular planning meetings help make sure they are supporting Steve to live the life he wants.

Steve has thrived since his move, takes great pride in his home and is keen to take responsibility for maintaining his home. He is a regular and familiar face around the village and the local pub and has been supported to go on holiday to the Lake District, is learning how to swim and is a keen walker. Steve visits his dad regularly and with support is now looking into employment opportunities in his local area.

Steve and his dad have felt very involved in the process of assessment and planning and this has resulted in an extremely effective support plan.

Emily's Story

Emily looks after her father, Angus, who is getting older and more frail and needs a bit of help around the house. She does the more heavy-duty housework such as vacuuming and mowing the lawn, as well as going to the supermarket and running errands.

Angus has a stroke and is taken into hospital. He is in hospital for three weeks and during this time Emily has a carer's assessment, organised by the hospital discharge team and the social worker from the Council. It establishes that although Emily was able to support Angus before the hospitalisation, the care required when he leaves hospital will be more than what she was doing before, including personal care, and she will need some support because of this. It is also not known how long the more substantial care will be needed for, as recovery following a stroke can be quite variable.

Emily will not be able to cope with this level of caring and uncertainty as she works full time and has two teenage children. She does not want to provide personal care for Angus, and he would prefer to receive this kind of support from paid care workers. She is still able to visit regularly, and helps with the housework when she visits, as well as picking up shopping, running errands and supporting him when the occupational therapist and physiotherapist visit.

Angus has an assessment himself and is offered support from the local authority, and after talking with Emily about how the support will fit in with the care she can provide, he decides to take support through Option 2, asking the Council to arrange support from a private care agency who can come and help him with showering, dressing and cooking at times that suit him. The care agency is flexible and will come along in the mornings and evenings to provide personal care and help with making meals. The care workers have shorter visits at weekends and on days when Emily is not at work, as she is able to help Angus with meals then and so the care workers only have to help him wash and dress.

A key safe is installed as well to make it easier for the care workers to access the property. It also means that other family members, such as Angus' other children and his grandchildren, can visit if Emily is not available.

"I let the council decide how to spend the money"

What is option 3?

Under option 3 you work with the professional working with you to choose the support that is right for you. The difference from option 2 is that you are not in charge of how the money is spent. This is commonly called 'arranged services' meaning services arranged by your council.

But taking option 3 does not mean that you have given up all control over your support. The council should still work with you to find support that is right for you. It just means that you let the council suggest which support you should have and, if you're happy with their suggestion, arrange it for you.

What if I decide I want to take more control?

You can decide if you want to take more or less control over your support. You need to speak to your social worker first and let them know it is not working out for you. Then there should be a review of your support needs. (see "Reviewing your support")

Rachel's Story

Rachel is 11 years old and lives with her family. She has cerebral palsy and requires the use of a wheelchair. Rachel has significant personal care support needs but attends mainstream school and lives life to the full.

She currently receives support from social work in the form of homecare twice a day to assist with getting showered, dressed and ready for school and bed. She also receives a sitting service one evening per week to allow her parents some time away from their caring role.

Rachel and her family are mostly happy with the support they receive but they do have some concerns. Such as sometimes the staff are not consistent and are often not as energetic and active as Rachel would like. Another concern is the sitter cannot take any responsibility for Rachel's siblings or friends who may want to visit.

Rachel's family get in touch with the social work and her support is then reviewed by her social worker who listens to the concerns raised by Rachel and her family.

After this conversation the social worker asks the homecare service to provide Rachel with consistent workers who are active and full of energy. She will also speak to the sitter service so Rachel's siblings and friends can also spend time with her doing activities they all can be involved in and work with Rachel in doing things that she enjoys.

When the homecare provider and sitter service agreed to this Rachel and her family were happy to continue to have their care arranged and provided through the council using Option 3.

Option 4

"A mix of options 1, 2 and 3"

What is option 4?

Option 4 is when you take a mix of two or more of the options for different parts of your support.

Why might I want a 'mix' of options?

Everyone's support arrangements are different and many people receive different types of support to meet different support needs.

The example below is about Vera who found that choosing a mix of options helped to support her more effectively.

This option may also be better for you if you would like to try the direct payment or managing the budget under option 2 for some of your support, but you would like the council to take care of the rest of your support.

Vera's Story

Vera is a 46 year old woman who has been diagnosed with a mental health problem. Her health varies and she can have days where she does not have much control over what she does.

Vera lives alone but has been assessed as needing some support. This includes support to manage bills and mail, support to keep good relationships with neighbours and support to keep on top of her housework. Vera also needs support with getting to health appointments and taking her medication.

Vera currently has daily support from a care provider but she doesn't always get on very well with the staff they send. This can make her health worse and can lead to her not taking care of herself and her home.

Vera's support is reviewed and these problems come to light during the conversations Vera has with the professional working with her.

Together they plan support that will help Vera get the support she

needs but will not lead to her getting frustrated with the care staff.

Vera chooses to have a mix of options for her support. She would still like care staff to be arranged by the council to come in to remind her to take her medication and help her to get on top of her housework. However she would like to use some of her budget to pay for art therapy sessions as she feels this helps to maintain her mental health and reduces her levels of anxiety. She asks the council to arrange the classes of her choice.

Vera has used a mix of the options to get the right support for her. She used option 3 to continue to get care at home arranged by the council and she used option 2 to get the council to buy art therapy classes on her behalf.

Planning your support

What is a support plan?

A support plan sets out how you will use your money to buy support and how that support will help you make the changes in your life that you want to make.

What makes a good support plan?

Having a good support plan is really important but how can you make sure you give the professional working with you the information he or she needs to develop a support plan with you?

To help you this guide sets out 8 important questions you should think about when planning support with the professional working with you:

- 1. What are the things and people that are important to you?
- 2. Where can you go to get the information and support you need?
- 3. What are the things that you can do yourself?
- 4. What are the main risks and how will we manage them?
- 5. What are the things you want to do?
- 6. How will you arrange your support?
- 7. Who are the people who can help you do the things you want to do?
- 8. What are the things (like information or funding) that will help you to do the things you want to do?

Advice and Information

- Remember you can ask your family members or a friend to help you at this stage.
- You can also get information and advice from a local support organisation.

Find your local support organisation. (http://www.sdsinfo.org.uk/)

 Could an independent advocate help you to have a stronger voice? **Find an advocate in your area**.(http://www.siaa.org.uk/find-advocate/)

Child's Plan

The Child's plan must be a single plan. If the child receives support from more than one public body or agency (such as support from the local council and the local NHS Board) it is up to the professionals to make sure their work is coordinated and recorded in a single plan.

What makes a good child's plan?

The child's or young person's plan should:

- be as simple as necessary and written so that it can be clearly understood by the child or young person, parents or carers;
- set out the child's or young person's:
 - Needs;
 - Strengths in their personal, family and environmental circumstances;
 - Risks that they face;
- be based on an assessment and analysis of the child's or young person's needs
- be practical, possible and achievable; and
- be regularly monitored and reviewed, and amended as needs or circumstances change.
- involve a range of different people such as
 - the child or young person receiving support;
 - the parents of the child or young person;
 - professionals from the agencies involved (such as social workers, teachers, doctors), and family and friends.

Other plans

A child may have another plan in place to meet other needs, for example additional support for learning and edducation needs. But plans for a child's health and social care needs should be combined into a single plan.

Reviewing your support

After a time, there will be a review to check if your needs have changed.



How will the council make sure my support is still working for me?

Your council has to make sure the support you get is meeting your needs and that it is helping you to do all the things that were agreed in your support plan. One way they will do this is by taking a review of your needs from time to time.

What is a review?

A review is when the professional working with you takes another look at your support, to find out if your needs have changed. They might decide that you need more support or less support.

When should a review happen?

Councils would like to review people every year but they should also do a review if your needs have changed or if you have asked for them to be reviewed. The professional working with you should tell you before your review and clearly explain what will happen.

What if things go wrong?

When can the council refuse my choice of support?

Councils and their staff have what is called a 'duty of care' which means that they have to be sure that any support they give you, or pay for, is meeting your needs. If they don't think the support you want will meet your needs then they can refuse to arrange it with you.

For children, the council must be sure that the support bought will keep the child safe and improve his or her welfare before it will agree to it.

The professional working with you should only refuse your chosen support if it is clear it will not meet your needs. If this happens they should:

- explain why the kind of support you chose will not meet your needs;
- help you to look at other kinds of support that might meet your needs, and;
- tell you about your right to complain through the complaints procedure.

What if I disagree with the professional working with me?

You should speak to the professional working with you, or if you can't do that you should speak to a senior social worker or a service manager. Then there might be a review which could solve the problem.

If you can't agree about your assessment then you might want to make a formal complaint through the council's complaints procedure.

What can you complain about?

You can use the local council's complaint process to complain about any of the following things:

- decisions about assessment and support, including the amount of money and time allowed for your support;
- the way your council arranged your support
- decisions made by professionals about your support

How do I make a complaint?

You can ask the professional working with you for information on how to complain. If you don't want to do that you can look on your council's website for information on how to complain or you can call their central contact number and tell the operator that you want to make a social work complaint.

What is the complaints procedure?

Each council's complaints procedure has three stages:

- 1. At first, every attempt will be made to resolve the complaint by the council;
- 2. If the problem hasn't been solved, it will be investigated by specially picked staff;
- 3. If the problem still hasn't been solved, you can ask for a Complaints Review

Committee to look into it. Complaints Review Committees will have some council staff but must also have some independent members as well.

What if I disagree with the result of the complaints procedure? After the local complaints procedure the Scottish Public Services Ombudsman (SPSO) (http://www.spso.org.uk/) will look at your complaint independently.

The SPSO won't usually consider your complaint unless you have already completed your council's procedure. If you are still unhappy after the council sends you their final letter about your complaint, please contact the SPSO as soon as you can. The SPSO don't usually look at complaints if the thing you want to complain about happened more than a year ago. They also don't look at complaints that have been dealt with in court.

Advice and Information

- Remember you can ask you family members or a friend to help you at this stage.
- You can also get support from a local support organisation.
 Find your local support organisation: http://www.sdsinfo.org.uk/
- Could an independent advocate help you to have a stronger voice? Find an advocate in your area: http://www.siaa. org.uk/find-advocate/

Your human rights

What are human rights and why do they matter to me?

Human rights belong to everyone, and they are a very important way of protecting disabled people. Human rights mean that the Government, hospitals and social services have to treat you with fairness, equality, dignity and respect.

It is helpful to find out about your human rights, especially if you are having a disagreement with your council or the professional working with you over how you have been assessed or how your support has been arranged.

Where can I find out more about my human rights?

The British Institute for Human Rights has produced a series of plain English, non-technical guides about human rights in the UK. They are written specially for people with mental health problems, disabled people, older people and carers. They will also be useful for people working with these groups, or people who would like to know more about how human rights affect these groups.

You can find these guides here:

http://www.bihr.org.uk/resources/documents/Guides

Find out more about Children's rights by visiting the website of Scotland's commissioner for Children and Young People: http://www.sccyp.org.uk/rights

Support and information

You can search for local organisations that can give advice and information using this website http://www.sdsinfo.org.uk/

Your local council might be able to give you details of local organisations that can provide help, information and advice. Or you might want to contact one of these national organisations.

SDSS

4, PURE Offices Bonnington Bond 2 Anderson Place Edinburgh EH6 5NP

www.sdsscotland.org.uk

Email: info@sdsscotland.org.uk

Tel: 0131 516 4195

SPAEN

Suite G4
Dalziel Building
7 Scott Street
Motherwell
MI 1 1PN

www.spaen.co.uk

Email: info@spaen.co.uk

Tel: 01698 250280

The Care Inspectorate has information on all registered care services. This includes ratings and reports that you might find helpful.

The Care Inspectorate

www.scswis.com

Email: enquiries@careinspectorate.com

Tel: 0845 600 9527

If you are looking for information on becoming a Guardian or getting Power of Attorney for a relative, or someone you care for, please contact the Office of the Public Guardian.

The Office of the Public Guardian

Hadrian House Callendar Business Park Callendar Road Falkirk FK1 1XR

Website: www.publicguardian-scotland.gov.uk

Email: opg@scotcourts.gov.uk

Tel: 01324 678300

These helplines can also help you with information and advice about your support

Alzheimer Scotland 24 hour dementia helpline 0808 808 300

Care Information Scotland. Care Information for Older People. Helpline 08456 001 001(Phone call rates) seven days: 8am to 10pm

NHS Inform 0800 22 44 88

Update Disability Information Scotland 0131 669 1600

Appendix: Jargon Buster

Assessment

The process of working out what your needs are and how you would like them to be met.

It should involve you, a professional (such as a social worker) and other people that you choose to help you, such as a family member.

Broker

A person whose job it is to provide you with advice and information about what services are available in your area, so that you can choose to purchase the care and support that best meets your needs.

Direct Payment

The council pay money directly to you and you arrange your own support by employing care staff or buying services from one or more organisations.

Eligibility Criteria

The council's rules on who can get support. The rules are based on the level of risk to a person if they do not get support.

Independent Advocacy

An independent advocate is a person who could help you to have a stronger voice when speaking with your council. An independent advocate will help you get the information you need to make real choices about your support.

Independent Living

Independent Living means all disabled people having the same freedom, dignity, choice and control as other citizens at home, at work and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.

Individual budget

Money that is allocated to you by your local council to pay for care or support to meet your assessed needs.

The way the budget has been decided should be clearly explained by the professional working with you. You should be given the chance to agree the budget before the support plan is put into action.

Outcomes

Personal outcomes – Defined by the person as what is important to them e.g. It is the difference or positive impact any support plans or intervention have on a person.

Personalisation

A way of thinking about support which puts you at the centre of the process of working out what your needs are, choosing your support and having control over your life.

Self-directed support is an example of personalisation.

Personal Assistant

A person who provides support to you who you directly employ through a direct payment (Option 1).

with you

Professional working A professional who works with you and your family to help improve your life by arranging to put in place the things you need.

> This is often a social worker from a council but it can sometimes be a professional from the NHS, such as a nurse or therapist.

Resource Allocation System

A Resource Allocation System is a means of deciding how much money people are entitled to, to be able to purchase he support they need.

Risk assessment

An assessment of the risk to your health, safety, wellbeing in a particular situation.

Support Organisation This is a person or organisation that helps you access, plan and maintain the support you need. This could include assistance with assessment, information on SDS, advice, support in using individual budgets or other forms of SDS and support in recruiting and employing personal assistants and payroll.

Support provider

The person or organisation that gives you the support you need.

It could be:

- An organisation that provides staff and other support to you (sometimes people call these care providers or care agencies).
- A personal assistant that you employ to support you
- The council or the NHS
- Or any organisation that provides a service that could help you

This has been produced in partnership by the following organisations:









