

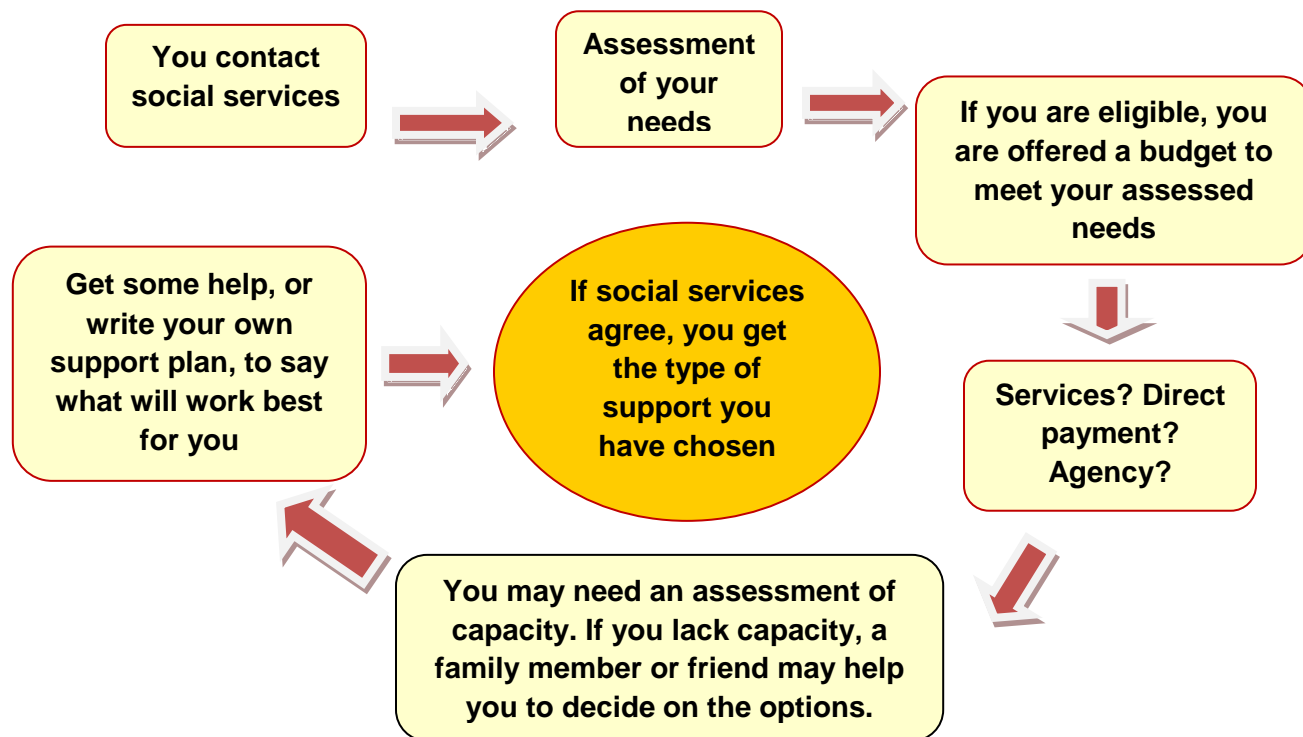
Planning your own support



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What is a support plan?



Things are organised differently in each area, and your own social services department should be able to help, by giving you local information and guides to support planning. At the end of this leaflet, we have included a general list of useful sources of advice.

We would like to thank all the people who took part in the 'Support Planning in Practice' research, and told us about their experiences.

For a summary of the findings please see: <http://www.bristol.ac.uk/norahfry>.

We have also produced a DVD called 'Speaking up in your Support Plan' for people with learning disabilities and those who work with them. If you would like any further information or a copy of the DVD, please contact a.torrington@bristol.ac.uk or for any more information val.williams@bristol.ac.uk

Planning your own support

A personal budget will give you lots of choices. You can get services from the council directly, or you can use agencies to supply care workers, or have a direct payment.

This leaflet is based on research between 2009 and 2012 with people who have learning disabilities, older people including those with dementia, and people with mental health problems. We also talked with families who were managing budgets for their disabled relative.

If you are starting to plan your support, using a personal budget, then we hope the points in this leaflet will be useful to you. The leaflet contains examples from people who use personal budgets in the six places we went to, but of course the exact detail of their experiences may be different from your own.

Contents

In each section of this leaflet, we have quoted directly from the 2012 White Paper, 'Caring for Our Future', linking our findings to what the government says should happen. We have also made some links with the targets set in *The Adult Social Care Outcomes Framework*

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The people and organisations that are there to help you

Some people can plan their social care for themselves. They write a support plan, so that social services can see how they are planning to spend their personal budget. But most people would choose to have someone to help them. That was what our research was about – we went to places where there were independent “support planners”, as well as social services. The independent support planners were from the voluntary sector, particularly disabled people’s own organizations.

A key principle in the the White Paper, ‘Caring for our Future’ (DH, 2012) is to

‘improve access to independent advice to help people eligible for financial support from their local authority to develop their care and support plan’.

During 2011-12 we talked to 23 people who had learning disabilities, mental health needs or had age-related services. We also followed up 12 people over a period of four years.

People in our research said that they need to know that they could get good advice. But they wanted to have someone who trusted them to make their own decisions. They particularly valued the kind of help they got from independent support planners and disabled people’s organisations.

One man with learning disabilities said that the People First group had helped him to be confident in saying what he needed.

A woman with mental health problems said how wonderful it was to have a support planner who went out for a coffee with her in the park. The support planner had time to get to know her, and she felt she was trusted to make her own decisions in small steps:

It was lovely surroundings, it was relaxed, it was usual territory, so I didn't feel threatened that I was going into some building or office that I didn't know, it was somewhere that I did know.

Your support plan can give you a sense of purpose in life

'Caring for our Future' (2012) promises you will be able to say:

'I am in control of my care and support'

A support plan should belong to you. It is your chance to say how you'd like your support to work for you.

People in our research said how important it was that a support plan should focus on how YOU see your life, and the outcomes you want, both longer term and short term. It's not just about being on the receiving end of support: it's about how you want to contribute, and what will give you a sense of purpose.. This is what two people who use personal budgets in the research had in their support plans:

The most important things to me are security and safety of home, certainty of personal relationships, certainty of working relationships, support.

The most important things to me, I would say my independence, the ability to do what I want when I want. And to feel valued, as though I'm giving – how do I put it? As though I'm doing something worthwhile. I'm not just wasting my life.

There were problems for some people when they were told by support planners what was good for them. Some people and their families were not aware that they had a support plan, but that was not the case when they were well supported by an independent support planning organisation. People said they wanted to decide for themselves when to take risks, and to be in control of managing their own affairs.

One young woman with autism and learning disabilities was encouraged by her parents to go out locally by herself. As one family member said: "She's part of the community and everybody enjoys looking out for her, making sure she's safe, you know."

Some older people particularly valued the chance to look back at their past. One person said '*We used to go to a lot of art exhibitions*', and another said they loved travelling, and foreign languages. Another person had been in a management job, while another had been an odd-job man in a builders' yard. All these things in your past can be important to take into account, when you are thinking of the future.

An informal, friendly approach

'Caring for our Future' (2012) promises you will be able to say:

'I know that the person giving me care and support will treat me with dignity and respect'.

Each person using a personal budget is different, and so each support plan will be different. But the most important thing is that you do it in the way that feels right to you, and that makes sense to you.

It is important to have the right kind of help, so that you don't feel the support planner is taking over, or telling you what you can choose. In our research, people said it was helpful to have someone who was good at listening, but also challenged them to think further. They generally liked an informal approach, and particularly valued meeting someone who had been through support planning themselves or had direct experience.

One support planner from a voluntary sector organization had got to know a young person with learning disabilities, called Donna, over a period of time while she was at school. She approached her as a friend, and Donna's mum recalled: "*Do you remember Nicola used to come and take you out, and you used to go up to town for a hot chocolate, didn't you, and talk to Nicola about all the things you liked, and what you'd like to do if you had the money to do it and the support.*"

The wife of a man with dementia particularly valued getting advice from someone who'd been in a similar situation to her: "*she'd actually had her husband with Alzheimer's, and she's been through this. So she's particularly good because she actually knows.*"

People said you should be able to decide where you do your support planning, and when. It can make a real difference if you feel relaxed. It should feel like a 'conversation with a friend'. For some people in the research, a good support plan was one which took their communication needs into account, and broke things down into small steps. One man with learning disabilities had a picture of him riding his bike on the front cover, and his support plan stated that 'it was all about him and his life'. Other people only wanted to have a plan which helped them work out how many hours they could employ their support worker.

Understanding the personal budget system

'Caring for our Future' (2012) promises you will be able to say:

'I understand how care and support works, and what my entitlements and responsibilities are'

People in our research seldom understood at first what a personal budget was all about. They said they wanted a 'route map' of the process, and a plan of the system, giving names, or at least roles and contact numbers for the different people involved. For instance, several people were unclear about what support planning actually is. Writing your support plan is different from an assessment of your needs. An assessment should record what difficulties you may have, what you need, and what you're entitled to. In many areas, there will be a special form on which you and your social worker will write your assessment.

Once you know what you're entitled to, then you can decide on the outcomes you want, and how to achieve those outcomes in your plan. In our research, people said that the support plan was often confused with the assessment. But when they got help from an independent support planner, things were clearer. Information was only trustworthy if it was accurate. Several people said that what they really needed was someone to coordinate things, and work with them.

Marion was an older woman with dementia living with her daughter, who contacted social services to see if they could get some help. The social worker came to do the assessment, and said that an independent support planner would come to help them with the next step. When the support planner turned up, she gave them a rough idea of how much the budget would be, so that they could all sit down and write the plan. Marion said she didn't want strangers coming into the house, so the support planner helped her daughter to find two people who were already known to the family, and would be able to take on the role of carer on two days during the week. This was specifically to help Marion go out more.

These parts of the process were especially unclear:

- The validation process, which happens when the support plan goes back to social services to be 'agreed'. These are called 'risk enablement panels' in some areas.
- The review process, in which support plans should be reviewed annually. People said that it helps to have an understanding of how the process *should* happen, as they can then shout more loudly to make sure that it *does*.

The options for how to use your budget

Caring for our Future' (2012) promises that:

“People will have control of their own care and support, so they can make decisions about the options available”.

A personal budget is the sum of money that is agreed for your social services support. You should be able to choose whether you take the money as a direct payment or provided support, whether you want to employ your own support workers, or perhaps go to an agency that employs the staff for you and sends them out to you. Some people had part of their budget as a direct payment, but also used a service like a day centre. Some people in our research had money to use for entrance fees for sports centres, or other activities, and equipment they needed, such as computers or art materials. There are lots of options, and in our research people told us about what helped them to make these choices.

One parent helped her son Jamil, who had learning disabilities, to manage his budget, and she bought in assistance from an agency. But she said: “I think I'm learning, and I want to sort of do a payroll myself. I'm thinking about it”. This parent had help from a user-led carers' centre, which gave her advice about her options.

Another woman who had mental health problems was assisted by a support planner from a disabled people's organization. She told us how useful it was to have all the options explained. The support planner had helped her to search around for the best agency for her.

One of the best ways of getting information about the options for a personal budget was to have examples of how other people managed things. For instance, the Alzheimers Society had helped people in one area to get together with their family members, and share experiences.

One of the issues in using agency support is that it is more expensive per hour than doing it yourself, and so you might get fewer hours. However, several PB users and their family members shied away from direct employment of their own support staff, because of the responsibilities involved. They said how important it was for the support planner to tell them about the kind of help they might get in managing the budget in the longer term.

Community Choices

People in this research wanted to do the same sort of things as anyone else in the community. Some people were very private, and just wanted a good home life. Some older people wanted to carry on with their interests in life, such as music or art. Many people valued relationships, and wanted to meet new people, including those who they might get to know more intimately.

Once people have their personal budget agreed, they still have to find ways to put it into action. This often involved knowing what might be available in the local area, including using a wide range of community resources. The biggest problem people told us about in the research was to do with information about local opportunities. The type of information you get will vary from place to place, but these were the things people said were really useful:

- Information about the local services, agencies, organisations or opportunities for you. This type of information can change quickly, so it's important that it's up to date.
- Examples of what has worked for other people in the same position.
- Accessible information that you can understand.

Molly was a woman with dementia, and her husband was her main family carer. They had a visit from a support planner who gave them good information: 'She gave us a list of names, who to ring and where to contact, it was brilliant'. She also explained to them how the system works, and left them with leaflets. This meant that the family was more in control, as time went on, and knew the kinds of activities and support that was available locally.

- People wanted, but only rarely had, a central point of information – someone to coordinate and help with queries.
- People valued having a flexible support plan, so that it wasn't tied to particular services or activities.

Some disabled people's organizations played a role in involving personal budget users in groups and activities. This was generally very much valued, and opened up people's horizons.

Family members: supporters and decision makers

This is what the Government Targets for 2013-14 aim for:

**Carers can balance their caring roles and maintain their desired quality of life;
Carers feel that they are respected as equal partners throughout the care process.**

Family members have several roles in personal budgets. They not only make decisions and manage budgets, but they are often providing direct care as well. Two-thirds of the people in this study had family members who were a huge part of their day-to-day support. Their support plans would not have worked without those family members.

It is important for family members to have their own needs assessed, but it was not clear whether they had had full carer assessments. Instead, they were often simply offered short breaks, so that they could continue caring for their relative.

Tim was a young man, who helped his father who had dementia. This became quite a full-time job, and Tim's dad did not like having paid carers in very often. But sometimes Tim felt he just needed a break, and to have time to just 'be himself'. He said: *It doesn't matter how much you love whoever you're caring for, you do need a break yourself. People tend to forget about the family who's there all the time, giving back-up and support.*

There were two main messages from the research here:

- Some people with learning disabilities did not want to get too 'tied' to the support they had from their family member. They wanted more independence, so that they could enjoy family relationships which were not about care.
- Other people, particularly families of older people with dementia, said that they wanted the support plan to take into account the disabled person AND the family member. They often wanted to do things together, like go to drop-in clubs, or have a short break.

Family roles can be complex. At least ten of the people in our research had a family member who managed all the big decisions about their budget for them. Sometimes these decisions were made for the personal budget user, because they had been assessed as lacking capacity under the Mental Capacity Act. However, people needed far better information about these processes.

Sorting out the finance

People in our research, and their families, said that the more they could understand about the money, the more they were in control of making their own choices. However, some people did not want anything to do with the money. You can choose to leave this to a support planner, or to your social worker.

Once you know roughly what your budget will be, you can work out how it will stretch, to pay for all the things you need. In our research, people who had independent support planning found that this process was far more straightforward. People who chose to employ their own staff with a direct payment, said how important it was to remember:

- Extra costs to recruit staff
- Contingency money – this is some extra that you need to keep in case of staff sickness, or emergencies
- The cost of managing the direct payment. This may mean a computer, or mobile phone bills, office costs.

Your social services department may have a 'template' to help plan the budget. There are also other tools mentioned in the resources at the end of this leaflet.

One mother of a young man with profound and multiple disabilities worked out the support plan for her son, with some help from another parent, who worked for the local disabled people's organisation. The social worker for her son was good at working together with this organisation, and took over when the plan had to go back to social services and to be validated. She felt that the plan was very reasonable, given the young man's level of needs, and she was able to advocate for the family at the panel who agreed the level of budget. Everything worked smoothly and the budget was soon in place.

In order to be 'in control' of their budget and their support, flexibility in the support plan was important. People did not want their money to be tied to particular things. However, it was hugely important for people in our research to have good advice about finance. A real problem arose when they had independent advice about their budget, but this did not tie in exactly with social services rules and regulations. Therefore, it was important to check out what social services would 'allow'.. Ongoing advice from disabled people's organizations was useful here.

Managing the budget

Half of the people in our research had family members who helped them manage their budget, but many people do manage things for themselves. If you have a direct payment, you need to open a separate bank account. Both family members and personal budget users said that it helped if there was good back-up to help them manage the money. They often had worries about their budget:

- People worried about whether they were spending money on things that were allowed
- They also worried if the money would stretch – some people felt they simply needed more.
- Personal budget users and their family members had to keep records of what they spent. Some people found that hard, others found it easy.
- When a review came up, people often said that it was ‘just about the money’, and no-one really asked how things were going.

This sounds like there were lots of problems. But many people managed budgets easily, when they had good support. They often got this from other people, including the people they employed, and from support organizations.

Jane was a young woman with learning disabilities. She employed three personal assistants, and her mother also assisted her at times. She was in control herself, but she needed help to sort things out. She had chosen to go to a small support organisation, which was always there for her in case she had a problem. She could simply ring them up and ask them.

Good support planners know how to work well with parents and other family members. Sometimes the family member was taking on a big job, in managing the personal budget for their relative. In some places, families always had a ‘trust’ to help them. That was usually a small group of friends or other family members.

Many family members who were managing budgets for their relatives needed back-up, information and guidance. Good, independent carer centres, or other voluntary organisations really helped family members who were managing budgets.

Getting on with things: life moves on

This is what the Government targets for 2013-14 aim for:

“People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation”.

The final theme in our research was that people’s lives changed. Their support plan also had to change, as their lives did. One person with mental health needs said:

Support planning is something that's going to have to be done two or three times at least. You know? And at the end of the day, if you look at a normal person's life, their needs when they are 20 are different from when they get older.

Therefore, it is important that the plan is simple and flexible enough, so that you can make changes yourself. If social services agree that the outcomes you’re aiming for are OK, then you should be able to make changes to how you spend the money.

People in this research told us that they faced problems about reviews. An annual review should help them to determine what their longer-term needs were, and to discuss any changes they need. However, they often found that their original social worker had moved on, and that the annual review was just a financial matter. These are problems which we will report on in our research.

In the long run, the people in our research who had flexible plans were most happy about their support, in the long term. They felt they were in control of things.

A young woman with learning disabilities employed three personal assistants with her budget, including a member of her family. She lived in an independent flat, near her parents’ house, and valued the fact that she could make decisions to change the way her support worked. She had chosen to move to a small organisation that gave her support with managing her direct payment, in the way that worked for her. She said:

“When I first had to be an employer I didn't really know what to do or how to handle things. In the past, people have actually made decisions for me, or tried to persuade me to do it like this or that. But now I am the employer. I can ring up if I'm not sure about something, and the (organization) always gets back to me.”

On the second visit we had, she was thinking of taking up some more paid work, and also joining an art group.

Resources and further information about support planning

There are many guides, both local and with national scope, that you can find on various websites, including the ones shown below. Do always search on your own Council's website, to see what they are providing.

- Sheffield City Council provides some very useful materials in their "Support Planning Toolkit"
<https://www.sheffield.gov.uk/caresupport/adult/how-get-support/supportplanning/sptoolkit.html>
- The 'In Control' website gives you a guide to support planning, with some stories about different people's plans, further resources, and links to training opportunities:
www.supportplanning.org
- Richmond Users Independent Living Scheme describe your rights and what support planning can do for you.
www.ruils.co.uk/Support-Planning-&-Brokerage/7/
- A tool created by a parent, for other families who are trying to cost out intensive support for a disabled relative on a 24/7 basis:
www.247Grid.com
- Lincolnshire toolkit and templates for person-centred support planning:
http://community.lincolnshire.gov.uk/Files/Community/164/Support_Plan_Tools_Template1.pdf
- The website called 'Think Local Act Personal' (TLAP) is full of useful resources, including a guide to support planning and brokerage for older people and people with mental health problems:
http://www.thinklocalactpersonal.org.uk/library/Resources/Personalisation/Personalisation_advice/SPB_Final.pdf

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