

Self-directed support

Mental health and self-directed support

Self-directed support is for everyone who is eligible for social care funding.

This fact sheet answers some of the most commonly heard questions about how people with mental health problems can, and should be included and gives links to useful sources of information and evidence.



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The basic facts

Self-directed support is an approach which builds on the work of the Independent Living Movement and the Recovery Movement of individuals living with mental ill health. It is a universal replacement for the current social care system, and as such must be made equally available for everyone with social care needs, of any age, who meets 'fair access to care' criteria.

People should have equal access to the choice and control over how we want our support needs to be met, regardless of what diagnosis we may have. We need to make sure that people with mental health problems are not discriminated against or left out of the new ways of having support in our lives. We also need to support a shift towards everyone being seen as 'whole people' with strengths and gifts to contribute as well as needs to be met.

Personal budgets for social care have been around for some time now. So far, many people with mental health problems have not yet had access to a personal budget. There is growing evidence that having a personal budget which allows us to have more choice and control leads to us having better lives, and this seems to be especially true if we have mental health problems.

Until recently, people who had their support from the NHS did not have the same choice and control but this is changing. In Control and the Department of Health are taking forward work to develop the use of personal health budgets in some parts of the country, currently through pilot programmes. More information on these can be found in our fact sheet on Personal Health Budgets.

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More information

It's important to answer some common questions and concerns. We've listed a few key facts below and there is more information on all of this on our website. Some useful documents which explain things in more detail are listed at the end of this fact sheet.

Can personal budgets in social care be used if we have a condition which changes, and which means the way we feel and think, and our ability to make decisions, might change quite often?

Yes absolutely. For anyone who sometimes can't make their own decisions or whose situation changes frequently because of a change in their health or social circumstances, the support plan must include a back-up plan for what should happen if a crisis occurs. The back-up plan must also state who is the person to take control of decisions and how money is spent during the times that the person themselves is not able to do that.

Do I have to take control of money and employ people through a direct payment if I find this too stressful?

No. Self-directed support is not about being forced to do anything. But it is about everyone having equal access to choice and control in ways that work for all of us. People with mental health problems, alongside everyone else, are entitled to know how much social care money you can have control of, but, like everyone else, you do not have to take control of the money through being paid it directly, or employing people yourself if you don't want to.

Best practice is that everyone can have control over decisions over how their money is spent, (once agreed through an approved care plan), but that the money itself can be held by another person, or another organisation, on your behalf.

Do I have to choose something different or can I stay with the services I know and have come to rely on?

No you don't have to choose anything different if you like how things are at the moment. What's important is that you come to that decision with all the information and support you want.

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Some people when offered a personal budget like to stay with things they know, value and trust. Some people like to change things gradually and choose to do new things with some of their money and keep some things the same. Some people once in control of their support money choose to put in place a fully new way of doing things.

We all want to either keep things the same or make changes, at a time and in ways that make most sense for us. None of us like to be rushed into picking up more responsibilities or changing things overnight. Best practice is that there is a support planning process which is sensitive to everyone's unique sense of well-being and self-confidence, which allows enough time and which avoids any kind of "all or nothing" approach.

**How does a personal budget deal with managing risk?
Would it mean I would not ever be put under a section of the Mental Health Act and have control taken away?**

A personal budget gives everyone a good opportunity to really think through the choices and options available for doing the things that really matter in our lives and to consider what things are OK and what is not. Good practice would be making sure that there is open discussion about different ideas of risk and how much freedom any of us are allowed and that decisions and reasons are written down clearly. Our fact sheet on managing risks and safeguarding explores this more.

You can still be put under a section of the Mental Health Act. However, some people are finding that being in control of their support is helping keep them well and out of hospital, and avoiding being sectioned. This might be one of the most exciting and useful aspects of being more in control of our support and more actively in agreement with our support plan.

How does the personal budget care plan fit with the care programme approach plan? Do I have to have more than one plan?

In Control believes that your support plan should be the one plan which you, the health and social care professionals and commissioners, and anyone else whom you want included, is involved in creating and agreeing. It should be possible for the plan to include parts to deal with the things Government policy says must be in a care programme approach plan.

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However, it's still early days and it might be that you are expected to have two plans at the moment, where you live. We are working to support having one plan, your own plan, as best practice.

My dad has dementia and can't tell anyone any more what matters most to him. How can he write a support plan?

When someone has any ongoing condition which means that they aren't able to tell people what matters most to them, then someone who knows and cares about that person can write the plan on their behalf. Of course people who don't use words but are able to communicate in other ways should be supported to give their views using communication tools and taking sufficient time for the plan to be put together. If someone is not able to communicate at all, and has no-one who can speak on their behalf, then your local council can still try to find out as much as possible about what the person is most likely to want, by talking with their friends, by learning about how they've lived their life so far, and finding out that way.

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An example

These examples have been taken from “Support planning and brokerage with older people and people with mental health problems” Department of Health 2010.

Pauline plans for if things get worse

Pauline’s goal was to stay out of hospital and move forward from the unstable situation she felt she was in. For eight years, she received direct payments, meaning she spent only six weeks in hospital each year compared to the many months prior to that.

Her new goals were modest: to move into her own home and get a job. She worked out a support plan based on what many may describe as a fluctuating condition. Pauline has psychosis, which means she sees things and becomes unable to manage for herself, but at other periods, she is really well and able to carry out a responsible job.

For some people, this instability means they live a quiet life waiting for an episode to occur. Pauline instead planned for the difficult period so she can be prepared. When she is well, Pauline only uses two or three hours of support per week, but when she becomes unwell, she has up to 24 hours of support. Importantly, she has a permanent support worker who does as few as three hours or as many as 20 hours per week.

Pauline’s weekly amount as a direct payment has been worked out over the years. Now she has also appointed someone else who can spend on her behalf. That’s because the time she needs to spend most of the payment is usually when she is not able to manage it herself. The funds build up in her account for when she really needs it.

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Sarah achieves change through having what matters most to her respected.

Sarah has an Obsessive Compulsive Disorder. She loves cats but her house used to be in a 'terrible state'. Support workers wanted to help Sarah get it cleaned but she couldn't bear people moving a single chair. The local Independent Living service was able to organise support with Sarah at a time that worked for her and at her own pace. When developing the support plan, her team spent time explaining that it wasn't about what they wanted, but what was right for her.

Sarah geared her plan around small things like buying a filing cabinet to put her possessions in. She wanted a new carpet but took a while to get to that point. While doing so, she began to think about her appearance and asked if she could go to the hairdressers and it was during this time she began to think that she did need her house cleaned. There was a stage in her life when Sarah wouldn't let the gas man in to take a reading, but by the time of her review, ten months later, Sarah had had the whole house cleaned with new carpet laid, new cabinets in the kitchen and a computer.

The support planning process helped Sarah think about how people responded to her, reflect on how she felt and just how much she had achieved. The support planner had stayed focused on what mattered to Sarah, and this helped build her confidence to make changes herself, at her pace.

Frank planned on behalf of his wife who had dementia

Frank looked after his wife Betty, who had dementia, before she passed away in December 2007. "I went through getting a personal budget with my wife. We only had it ten months and before that, I had to do everything for her."

They went through the support planning process with a broker that was organised by the council. Frank said he didn't mind the process and he had to speak on behalf of Betty. He spoke all about their life and their interests in caravanning, photography and ballroom dancing. Eventually they received support from two personal assistants in the morning, and two at night.

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**There is a lot more information
on the In Control website:
www.in-control.org.uk**

**Some more information and research about
self-directed support and mental health:**

“Putting Patients in Control”

Vidhya Alakeson, Social Market Foundation 2007

“International Developments in Self Directed Care”

Vidhya Alakeson, Commonwealth Fund 2010

“Personalisation in mental health” Simon Duffy,

The Centre for Welfare Reform 2010

**“A Voice and a Choice – self-directed support by people
with mental health problems”**

Rita Brewis 2007 In Control

**“Recovery Budgets in a Mental Health Service- Evaluating recovery
budgets for people accessing an Early Intervention Service
and the impact of working with Self Directed Services on the
team members within a North West of England NHS Trust”**

David Coyle, Faculty of Health and Social Care University
of Chester July 2009

**“Support planning and brokerage with older people
and people with mental health difficulties”**

DH 2010.

“Mental Health and Self Directed Support”

Carey Bamber Senior consultant Care Services Improvement
Partnership North West Peter Flanagan Strategic partnership
Manager Yorkshire and Humber Care Services Improvement
Partnership Mental Health Today 26 July/August 2008

National Mental Health Development Unit: www.nmhdu.org.uk

**Stories and personal accounts on National Mental Health
Development Unit website:**

www.nmhdu.org.uk/nmhdu/en/our-work/personalisation-in-mental-health-emerging-programme/film-and-media-learning-resources-to-download/

About the In Control and Me project

A three-year project to produce accessible information for everyone who wants to direct their own support, funded by the National Lottery through the BIG Lottery Fund. You can find out more at www.mencap.org.uk/incontrol or www.in-control.org.uk/icandme

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