

Personalisation in mental health: Breaking down the barriers

A guide for care coordinators



For better
mental health

Putting us First

This guide for care coordinators has been produced as part of a Mind project, 'Putting Us First', to ensure that more people experiencing mental distress have choice and control over their care. At the end of the project, we would like more people with mental health problems to be in receipt of personal budgets, and more practitioners to understand how personal budgets work in mental health. This guide looks at some of the barriers we know exist, and which care coordinators continue to grapple with, including those related to:

- eligibility
- the divide between health and social care
- risk and accountability
- bureaucracy and confusion in the system.

In 2009, people who use mental health services generally have little or no choice and control over the kind of support they receive. Personalised mental health services will change this, with greater use of direct payments and more flexible, personalised commissioned services.

We do not pretend to have all the answers, but we know that there are many creative practitioners out there who also want to make changes towards a more personalised system. We hope that we can move forwards together to find some of the solutions, and that this guide will help to do that.

Summary of key points in this guide

- People with mental health support needs have a right to greater choice and control over their services.
- Personal budgets are wider than direct payments. They will give people choice about how to organise their own social care and support.
- With support, people will be able to assess their own needs in relation to their mental health, know what money they have available for them, and plan for their own support.
- A holistic assessment needs to take account of a person's health and social care needs.
- Everyone should have good information, and have choice and control, even those who do not receive services.
- Block contracts will need to change, with the development of a resource allocation system (RAS) in each locality.
- People with mental health needs can be supported to identify risks, develop advance statements and make sure there is a crisis plan in place for themselves.
- Service users often want to keep up some of the group activities they do. That is fine, and people can have a combination of a direct payment, individual support and service provision.
- People's needs may fluctuate. A personal budget can work very well to enable them to have support when they need it.

If everyone works together, care coordinators will be well supported to understand the policies and processes in their own locality. Use this guide as a starting point and develop your own list of local resources.

Introduction: the present and the future

We already have a system of direct payments in England. Since 1996, mental health service users have had the right to receive social care services such as day centre places, personal care and family support through a direct payment. However, this guide is also about the future. In 2008, the Government published a strategy for transforming social care (Department of Health, 2008). The three year programme for change includes a commitment that everyone eligible for publicly funded adult social care support will receive this through a personal budget.

There is a long way to go to make this commitment a reality. Take up is still very low across the country, even for direct payments. In 2008, only 3,373 people were in receipt of a direct payment for mental health services. People with mental health needs are still usually placed into existing social care services, which often do not meet their individual needs.

Mind believes that the challenges in implementing government policy in mental health have led to inequality in the social care system, which may prevent many people with mental health problems living full, independent lives.

People with experience of using mental health services say that they want to be in control of their own lives, and of the support they need. Personal budgets are the opportunity to make this a reality, and provide a much wider range of choices than simply a direct payment.

There are a number of ways that people can choose to use their personal budget. It might be by:

- using existing services
- asking their care coordinator to organise services on their behalf
- asking an agent (or broker) to manage their money for them
- asking the local authority to transfer the money to an organisation or agency that currently provides services that the person wants to use
- receiving a direct payment
- any combination of the above.

There are a number of terms associated with personalisation that are used in this guide::

Personalisation: People with mental health needs having choice and control over their care, with support and resources provided by the local authority.

Personal budget: A clear, up-front allocation of money that a person with mental health needs can use to design and purchase support to meet their social care needs.

Individual budgets: Similar to personal budgets, but incorporating a number of different funding streams as well as social care money. The funding streams included in the pilot programme included *Supporting People* and the *Independent Living Fund*.

Direct payments: One of a range of options for people getting a personal budget. Direct payments are cash payments paid directly to the person, for them to buy their own support, rather than have their support delivered by the council.

The important role of care coordinators

Personalisation requires a change in the whole social care system and culture, so that all individual service users are empowered to have choice and control. Care coordinators are also central to these changes, and to finding creative solutions.

Our research has shown that in mental health, direct payments are still a matter of confusion for many professionals. This guide is therefore offered as a resource for care coordinators, their managers and other members of community mental health teams (CMHTs).

Personal budgets and direct payments are being organised and facilitated in different ways across the country. Therefore there are no solutions that can be immediately implemented in all areas. Local knowledge is essential in order to put this guidance into action. We aim to give you the basic knowledge and tools, so that you can work out ways to move forward in your own area.

Personalisation in a nutshell

Personalisation has its roots in the disabled people's movement. Independent living, participation, choice, control and empowerment are key concepts for personalisation and they have their origins in the independent living movement and the social model of disability.

- Direct payments became available in 1996, and although initially slow to be taken up, those who do use direct payments are very positive about the benefits. This has stimulated much of the thinking around personal budgets.
- The practical work of 'In Control' (see resource list), established in 2003, has had a large influence. 'In Control' pioneered the use of self-directed support and personal budgets. These were piloted across six local authorities from 2003 to 2005, initially with people with learning disabilities.
- Since then, the idea of self-directed support has been extended to a broader range of people using social care, and individual budgets have been piloted in 14 local authorities and evaluated in 2008.
- The Social Care Green Paper *Independence, Well-being and Choice* (Department of Health, 2005) first signalled the transformation of social care services towards personalisation in 2005.
- It was reinforced in the White Paper *Our Health, Our Care, Our Say: a new direction for community services* in 2006 (Department of Health, 2006), and again in the *Putting People First Concordat* in 2007 (Department of Health, 2007a).
- In 2008 and 2009, the Local Authority Circulars *Transforming Adult Social Care* (Department of Health, 2008 and 2009) set the target that by March 2011, councils should have made significant steps towards the redesign and reshaping of their adult social care services, with the majority having most of the core components of a personalised system in place.
- The Personalisation Toolkit (see resource list), an on-line resource to support councils to begin to plan and deliver the transformation of their social care systems, was launched in 2008.
- In Summer 2009, the first pilot sites will be testing out personal health budgets in England.

Breaking down the barriers

We have all heard many tales of the barriers and problems about direct payments in mental health. We have used some of these stories in this guide to focus on particular issues, which will be relevant to personalised services more generally. This guide will therefore help to understand:

- what personalisation means for mental health service users and for you as care coordinators and others involved in the delivery of personalised services
- how you can overcome some of the barriers to implementing Government policy within your own mental health team.

What is personalisation?

Personalisation is: "the way in which services are tailored to the needs and preferences of citizens" (Prime Minister's Strategy Unit, 2007: p.33). Independent living, participation, choice, control and empowerment are key concepts for personalisation, which have their origins in the disabled people's movement.

Personalisation ties in closely with the concept of 'recovery' in mental health, which is about the individual having choice and taking control of her or his life. It means starting with the individual. A personalised approach supports people to decide and direct what support they require. This does not mean people being completely on their own. It is your role to make sure people get good information and support, so that they can discuss what their needs are and decide how they would like their needs to be met.

What are the steps to a personalised approach to mental health?

A personalised approach to mental health will involve the following steps:

Step one

Person-centred needs assessment

People are encouraged to decide for themselves what their needs are, with support from professionals where necessary.



Step two

Resource allocation

An amount of money that equates to the level of need of the person is allocated. This is their personal budget.



Step three

Self-directed support

The person plans their own care, and creates or selects the support and services that they feel will best meet their needs within the budget allocated to them. People can have as much help as they need with this.

Step one Person-centred needs assessment

People with mental health problems should be encouraged and supported to identify their own needs. These may be needs in relation to mental distress that they are experiencing, or in relation to social, personal, educational, work or other areas of their lives.

In many areas, self-assessment questionnaires are being developed to facilitate this process. You can find out about these by contacting your own team manager, or by contacting a senior manager in social services.

A person-centred assessment is mediated and supported; it is like a conversation between the individuals concerned rather than a tick-box exercise. It is your role to make sure mental health service users get support in assessing their own needs.

Where to start

Barrier: “But I don’t know who to go to, or where to start”

Annika had a support worker from the community mental health team providing her with support twice a week. She wanted to have an assessment for direct payments so that she could have a support worker of her own choice who could work with her more flexibly.

Steps towards overcoming this barrier

Annika is already receiving secondary mental health services, and you are managing her care as her care coordinator.

Your first step is to make sure Annika has a care plan review meeting, to provide access to a personal budget. Care plan review meetings must take place as a matter of course at least once a year, but Annika has the right to ask for a review of her care plan at any other time. It is good practice to remind Annika that she has the right to ask for a care plan review.

At the review meeting, you should support Annika to assess her own social care needs. Using your local resource allocation system, once it is in place, (see Step two in this guide) you will find out whether Annika is eligible to receive social care services, and how much money is in her personal budget. Annika can then opt to manage her personal budget in a number of ways – one of which is to use it as a direct payment.

Annika does not need a social worker to be able to access a personal budget. If you are her care coordinator, you are responsible for assessing both her health and social care needs. Your role remains one in which you will help Annika to work out what outcomes she needs from her support. You will continue to have a role in making sure that she is able to achieve those outcomes, but the way in which she does so will be much more in her own hands.

Eligibility



Barrier: “But am I eligible for social care – or even for an assessment?”

Jon is receiving support from his GP for his mental health needs, but he feels that he needs more support than this. He thinks that his GP is only considering his medical needs, and does not consider the effect that his mental health needs have on the rest of his life.



Steps towards overcoming this barrier

Jon’s GP, may make a referral to see you at the CMHT, or Jon might approach you directly for a social care assessment. You will then assess Jon’s needs with him. Make sure you take a holistic approach, looking beyond his mental health symptoms, and consider all areas of how he might like to live his life, including work, training or education, social activities, child care or other family responsibilities, and managing to live safely at home.

It is helpful for Jon to be in control, by thinking about what his needs are, and what outcomes he would like to achieve, before going to the meeting. He could do this by keeping a diary for a few weeks to note down those times that he needed support, what he needed support with, and what type of support he felt would have been most helpful to him. He could also use one of the self-assessment tools for people with mental health support needs, such as CUES or the Life and Support Plan (see resource list).

At the meeting, Jon will tell you about his needs. In some areas of the country, you may have a questionnaire to help with this process – ask the personalisation lead in your local authority or health trust for more information about the tools you can use.

The eligibility criteria for receiving health and social care services are set by the local authority and primary care trust. The assessment and questionnaire should be able to tell you clearly whether Jon is eligible for social care support. You should then ask Jon to move on to Step two, by offering him a personal budget and support to work out how he wants his needs to be met.

If Jon’s GP does not think that he needs a referral to the CMHT, or if, as a result of the assessment and questionnaire, he is not considered eligible to secondary mental health services under the Care Programme Approach, Jon is still entitled to a personalised approach with information and advice according to his needs.

Step two Resource allocation

With the development of personalisation, your local authority should have developed a transparent and fair resource allocation system (RAS). This is so that people with the same level of need are allocated a similar amount of money to meet their needs. The resource allocation system is triggered by a needs assessment. According to the responses given during the needs-assessment, you will be able to tell your clients how much money is available for their support.

Lack of resources

Barrier: “But money is tied up in block contracts for services”

A care coordinator had heard her manager say that there wasn't enough money to provide personalised services for everyone, particularly if people opted for direct payments. She was therefore reluctant to mention different options to Bill, who she was key-worker to, in case he was disappointed.

Steps towards overcoming this barrier

In each area, commissioners and senior managers need to work together to ensure that money is allocated individually, and is available within local authorities and mental health services to provide personalised services. More information about developing a resource allocation system can be found in the Personalisation Toolkit (see resources list).

A personal budget will have to be worked out for all service users, and they can take that as a direct payment if they want to choose that option. A direct payment does not come out of 'extra money' – it is the same money used in a different way.

“Problems with internal budget management procedures may not be used as a reason to refuse or delay the offering or the start of a Direct Payment to a person to whom there is a duty to make a direct payment” (Department of Health, 2003: p.9).

Step three

Self-directed support

Self-directed support puts people at the heart of designing their own support.

“As a general principle, local councils should aim to leave choice in the hands of the individual by allowing people to address their own needs as they consider best, whilst satisfying themselves that the agreed outcomes are being achieved.” (Department of Health, 2003: p.6)

Once a person has been told how much money is available for them to meet their needs – their personal budget (see page 3 of this guide), you will ask them to develop a care or support plan. This shows how they would like to meet their needs and the outcomes that they want to achieve within the budget they are allocated. They can make their plan with support from family and/or friends (this is sometimes called a ‘circle of support’). You can also find out what kinds of support your local direct payments support scheme may offer, such as a ‘broker’ or advocate.

Remember that people will be able to choose a whole range of options for using their personal budget. Personalisation is not just about direct payments.

Once the care plan has been drawn up, it is reviewed by the person’s care coordinator, to be sure that it meets the person’s needs and outcomes in an acceptable way. When it has been agreed, the person can then put the plan into action. Again, you need to make sure people get support from a professional or a broker if they need it – the personalisation approach doesn’t mean that people have to do everything for themselves. Contact your local direct payments support service (a full list is on the website of National Centre for Independent Living (NCIL), see resource list).

Risks and vulnerability



Barrier: “But it’s too risky and people may be vulnerable”

Ahmed is Zak’s care coordinator. He was worried that Zak would be vulnerable and at risk if he were to arrange his own support, and particularly without someone from the community mental health team being in regular contact with him. He decided not to mention the new personalisation approach to Zak because of this.



Steps towards overcoming this barrier

Risk must not be seen as a barrier to delivering a personalised approach; indeed, personalisation should be no more risky than past approaches to delivering services. Part of your responsibility is to consider risk assessment and management with Zak under the care programme approach, and to draw up a risk management plan.


The aim of the risk management plan is to empower Zak to better manage any risks that he might face. This could include identifying risk alerts, having contact numbers available, using peer and third-party supports, supporting Zak in speaking up for himself or assertiveness training, and developing crisis plans and advance statements for Zak to use at times of crisis and to manage risk.

Just as with the provision of directly provided services, your care co-ordination role for Zak will remain the same under the personalisation approach, and your level of contact with Zak will be negotiated as part of his care plan.

Step three

Self-directed support

A mix of activities or support services?

 **Barrier: “But I don’t want to give up my group activity. How does this fit into a personal budget?”**

What Angie would really like to do is to volunteer at the local dog kennels, as caring for animals really motivates her. She would like a support worker to help her do this one day a week and to carry on going to the day service where she meets her friends on another day..

 **Steps towards overcoming this barrier**

Angie can choose to receive a mix of direct payments and the direct provision of services to meet her needs. She can decide on the balance of support that she wants.

You could arrange with the finance department of the local authority for the cost of one day a week’s attendance at the day centre to be transferred there on Angie’s behalf. Using the rest of her budget, Angie could employ a support worker of her own choice to assist her at the kennels, or she could pay a social care agency to provide a support worker for her.

It is your role to explain these options to Angie clearly, so that she can decide what is best.

Fluctuating needs

 **Barrier: “But some people’s need for support fluctuates”**

Mina has fluctuating needs. Some weeks she is relatively well, and at those times she attends college consistently. Other weeks, she needs lots of support to keep herself safe and well. Her support worker, Sahra isn’t sure whether Mina could manage her personal budget in these circumstances.

 **Steps towards overcoming this barrier**

Personalisation is not just for some people – it is for everyone. It can work particularly well for people with fluctuating conditions, by tailoring services and supports to suit the individual, at times and in ways that they feel would be most helpful to them.

“By taking account of the benefits in terms of independence, well-being and choice, it should be possible for a person to have a support plan which enables them to manage identified risks and to live their lives in ways which best suit them” (Department of Health, 2007b: p.4).

Mina could write out a crisis plan and advance statement, and guidelines for support workers that indicate the signs of her becoming more unwell and what she would want them to do should this occur. It may be that she has a family carer to help her with this. If she has not, you can give her support to do this, or find out what support may be available from an advocate or broker (see page 9). Like Zak, Mina could develop her own risk management plan.

If she has opted for direct payments, Mina should be able to ‘bank’ her support work so that she uses it at times when she needs it most. This may mean allowing her to hold a larger amount of ‘contingency’ money that she has not spent when

she is well, and employing 'as needed' or 'back-up' support workers on flexible contracts for when she is unwell.

You can also support Mina to consider how she would manage her direct payments at these times, so that, for example, if she is too unwell to monitor the timesheets of her support workers, alternative arrangements are in place.

If Mina is choosing to purchase existing services, you need to ensure that she is thinking about flexibility of service provision in response to her fluctuating condition, and that she is not paying for services at times when she does not use them.

Bureaucracy and paper work



Barrier: "But personal budgets sound like a lot of work"

As a care coordinator, Jayne was anxious about offering Chris more personalised services. She had never seen the process through with anyone, and thought that it seemed like a lot of extra work for her.



Steps towards overcoming this barrier

As a care coordinator, you also need to be empowered and supported. Personalisation is in line with basic social care values, and all practitioners should embrace these. Many will welcome the chance to get back to what social care should be about.

Your organisation has a responsibility to ensure that everyone is fully informed about the local authority's personalisation policy, and its operation within the framework of integrated mental health services.

You should receive training about the processes in place, so that you understand the roles of the finance department and the local direct payments support service and know how to contact them. They of course should also have a clear understanding and training about personalisation. If this training is not on offer, use this resource guide to approach your line manager.

Your knowledge of, and attitudes towards personalisation are likely to be influential to the service users you work with, and you shouldn't be left feeling alone or struggling in offering more personalised services. Ask for support from your line manager, and bring personalisation up during supervision sessions. Find colleagues who have supported clients in this way to find out more about the benefits of personalisation.

Resource list

CUES (Carers and users expectations of services)

A resource that provides a structure for service users to communicate their views about their experiences of mental distress and its consequences.

www.mentalhealthshop.org/document.rm?id=36

Direct Payments for Mental Health Service Users & Survivors

A practical guide to direct payments in Mental Health, written before the moves towards personal budgets, but still relevant.

www.ilsyork.org.uk/resources/NCIL-guides.php#guide-to-some-key-issues

In Control

The 'In Control' website is packed with useful guidance, information, and resources about self-directed support for all service users, including those who have mental health support needs. It includes individual stories and video clips.

www.in-control.org.uk/site/INCO/Templates/Home.aspx?pageid=1&cc=GB

Individual stories of using personal budgets in Mental Health

Inspiring, illustrative stories from individuals who have used personal budgets to support their mental health needs.

www.dhcarenetworks.org.uk/Personalisation/Topics/Browse/MentalHealth/?parent=2737&child=5126

Life and Support Plan. A guide for the Individual Budget Pilot Sites

A practical guide, with pages to photocopy for individual service users, in order to develop their own support plan.

www.supportplanning.org/Support_Planning_Downloads/SP_06Life_and_Support_Plan.pdf

National Centre for Independent Living

The NCIL website keeps a list of all direct payment support schemes. You can look up the scheme in your own area, if you do not already know where it is based.

www.ncil.org.uk/directory.asp

Personalisation self-assessment tool

This tool is for local councils with social services responsibilities with partners (such as mental health trusts). It aims to help them better understand what is required to transform social care systems from current models to a 'self-directed support' model that will support the delivery of the personalisation agenda.

<http://self-assess.personalisation.org.uk/csips/>

Personalisation: A Rough Guide

Written by Sarah Carr for SCIE, in 2008, this very popular and clear guide is intended to set out our current understanding of personalisation in its early stages as evidence emerges and problems are identified.

www.stoke.gov.uk/ccm/cms-service/stream/asset/?asset_id=1709268

Personalisation Toolkit

The Personalisation toolkit is an on-line resource to support councils to begin to plan and deliver the transformation of their social care systems, as set out in Putting People First.

www.dhcarenetworks.org.uk/Personalisation/PersonalisationToolkit/

The websites given in these references were all correct on 26 June 2009. If you have difficulty accessing any of the documents, the website address may have changed. You could try going back to the home webpage of each site, or simply putting in the document title into Google.

This guide was written in April 2009, a time of change – and we are aware that there will be many more changes. We hope that this guide will have challenged you, but also that it will help you to be part of shaping the transformation agenda yourself, and that you will be able to use it as a starting point to develop your own list of resources.

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Who we are

Mind

Mind has been speaking out for better mental health for 60 years. We work in partnership with around 200 local Mind associations to directly improve the lives of people with experience of mental distress.

Mental distress affects people from every ethnic background and walk of life – one in four people experience mental distress at some time in their lives and a third of all GP visits relate to mental health.

Mind believes everyone is entitled to the care they need in order to live a full life and to play their full part in society. Our vision is of a society that promotes and protects good mental health for all, and that treats people with experience of mental distress fairly, positively and with respect.

Mind is an independent charity supported by your donations. We campaign to influence Government policy and legislation, work closely with the media and are the first source of unbiased, independent mental health information via our publications, website www.mind.org.uk and phone service *MindinfoLine* 0845 766 0163.

Norah Fry Research Centre

Norah Fry Research Centre was established in 1988, and 2009 marks a celebration of 21 years of continuous research activity. Its principal interests are in the area of social and policy-related research. The Centre aims to make a positive difference to the lives of disabled children, young people and adults – and works with disabled people, including people with mental health support needs, to support them in taking part in research and development.

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For better mental health

For details of your nearest local Mind association and of local services, contact Mind's helpline, *MindinfoLine* on 0845 7660 163, Monday to Friday 9.00am to 5.00pm. Speech impaired or deaf enquirers can contact us on the same number (if you are using BT Text direct, add the prefix 18001). For interpretation, *MindinfoLine* has access to 100 languages via Language Line.

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