

Personalisation in mental health: Creating a vision

Views of personalisation, from people
who use mental health services



For better
mental health

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1. Introduction

Views of personalisation, from people who use mental health services

We have to stand as independent and to have our own input, with our own needs-led agenda, coming from bottom up.

Focus group participant

This report has been produced as part of a Mind project 'Putting us first'. The project aims to ensure more people experiencing mental distress have choice and control over their care, through a personal budget. People with experience of using mental health services say they want to be in control of their lives, and of the support they need. The personalisation agenda and the introduction of personal budgets is an opportunity to make this a reality, and provide a much wider range of choices than simply a direct payment.

This report presents the findings from four focus groups for people with experience of mental health services, held during March and April 2009, and led by researchers from the Norah Fry Research Centre at the University of Bristol. The venues were in Yorkshire, Cumbria, the South West and London. Twenty-six people attended these groups (14 men and 12 women), including a range of people using local Mind services, Mind members who are not currently using services, and a few people who have experience of direct payments.

The aim of the focus groups was to explore how personal budgets could change people's lives for the better. This report will be helpful for both statutory, voluntary and private sector mental health service providers, in creating a vision of what personalised services might look like, and what we need to change to get there.

The focus groups

In order to talk with a variety of service users in different parts of the country, we held four focus groups during March–April 2009. Each group was hosted by a local Mind association, and the venues were in Yorkshire, Cumbria, the south west and

London. Altogether, 26 people attended these groups, 14 men and 12 women. The discussions were prompted by a topic guide, but very much led by the concerns and issues participants brought to the groups. The discussions covered the following topics:

- a) Goals and aspirations of participants.
- b) Discussion and information about personal budgets and direct payments.
- c) A diary activity or small group discussion about people's everyday lives, and the things they would like to do in their lives.
- d) Sharing of ideas for personalised support.

All the discussions were recorded and transcribed, and the account in this report is based on a qualitative analysis of what people said. We are extremely grateful to all the participants for sharing with us their expertise and their creativity, and we hope the following account does them justice.

How we ran the focus groups

Potential participants for focus groups were approached through four local Mind associations (LMAs).

Participants responded to an advertisement sent out for the project by LMAs. They filled in a reply slip, and responded directly to the research team. This was for reasons of anonymity, and gave the 'Putting us first' project an identity which was distinct from the LMA.

People who came to the group were interested in discussing personalisation, and had made a positive choice to attend.

Two of the groups included input from a carer, which gave an opportunity to hear about the effects of personal budgets on carers, and also about the supportive role they may play.

A variety of activities was carried out in each group, which worked very well. The organisation of service user payments, consent sheets and other organisational matters all happened at the start of the meeting.

Part of a DVD produced by Yorkshire and Humberside Care Services Improvement Partnership about direct payments in mental health was shown at each group, and was successful every time in promoting good discussion and ideas.

We also gave people diary sheets, to fill in during the group in pairs or small groups. This was to help people reflect on the things they did now, and the things they would like to do in their lives. The feedback from individual and pair diary activities was successful on two occasions, and resulted in some very creative thinking.

Participants in the focus groups often discussed the barriers and particular problems facing them in the process of applying for direct payments. They often needed clear information and guidance about these issues, before moving on to the positive choices given by personal budgets.

In three groups, nearly all of the participants had not known each other before coming to the groups, while the fourth group consisted largely of people who were very familiar with each other and used to conducting group discussions. There was plenty of peer support offered by people in the groups, including exchange of contact details for local information.

Participants appreciated information given by the project, which focused on what direct payments and personal budgets are. There was little understanding of the latter, and the wider implications of personalisation, and participants were keen to ask questions and gain knowledge.

The length of each group was the same (two hours); however, the third group carried their discussion on into lunch. We found the timing needed to be flexible, as, for instance, one very talkative participant can lengthen the discussion quite dramatically.

The main planned goal of the groups was to gain service user views on potential uses of DP/PBs for mental health service users. On the whole, the format of the focus groups was very successful in achieving this goal.

Definitions

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 additional funding streams included in the national pilot programme for Individual Budgets included Supporting People and the Independent Living Fund. Other funding streams that could be included are: Access to Work, Integrated Community Equipment Services, and Disabled Facilities Grant.

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 local authority.

2. Summary

- Personal budgets can help people access ordinary activities and pursue their goals in life. They are also helpful in building confidence and motivation.
- Personal budgets provide more flexible support – particularly when people are coming out of hospital, back into the community.
- A personal budget can be used to employ a personal assistant (PA). But it can also be used to pay directly for activities or support services.
- Ideas for using personal budgets to meet mental health outcomes include the following. People want to:
 - live independently in their own home, or have support to improve their home
 - go out, perhaps with a PA to keep them motivated
 - have someone to confide in, so they could talk over problems
 - pay for a car, travel independently, or learn how to drive
 - pay for activities so they could keep up connections with other people, socialise and meet new friends
 - have support in maintaining close personal relationships, and pay regular visits to family members or loved ones
 - pay for computers in order to communicate with others, and have support to learn the skills or to pay for internet connection
 - be able to afford holidays, or get support to go on a short break, to support their mental wellbeing
 - pay for educational courses or materials, or have an assistant to help with studying, or motivation to study
 - contribute to society, and have support in carrying out volunteer activities, as well as paid work
 - take out membership of a gym, or a sports club, so they could get physically fit, and combat the effects of medication
 - tackle mental health distress by choosing their own alternative therapy or counselling
 - pool personal budgets, so they could keep group activities going, and have peer support.
- Knowledge of direct payments is confused. The move towards personal budgets is even more widely misunderstood. Clear guidance and information for service users, care coordinators and local managers is urgently needed. Mind's Putting us first project will seek to address this need.

3. Ideas about the process of personalisation

- Experiences of accessing traditional services or direct payments are often confused and full of problems.
- Participants said there is an urgent need for personalisation.
- They want a clear, transparent system for organising support services.

The need for a new system to access support

It is vital personal budgets are organised in a way that is clear, open and easy to access. At the moment, participants' experiences of access to support services are far from personalised. They were clear they want more individually tailored care packages, and personalisation has a lot to offer, but it doesn't exist for them at the moment.

A major problem is access to care coordinators or social workers:

As far as social workers are concerned, when you need to see them, who's there for you?

A lack of access to services transferred over to participants' feelings about personal budgets. There are many fears, as well as confusions, about how people would get access to a personal budget. Some people had tried to be assessed for a direct payment, for instance, and the problems they identified were:

- a) not having a care coordinator
- b) too much paperwork
- c) and a system that is already overloaded and professionals who are burnt out.

Confusion about direct payments and benefits was also aired; people want a new system that is under their control, but they feel a lot of the 'old' problems might transfer over into personal budgets.

The current system for getting a provided service, or a direct payment, is seen as too bureaucratic and sluggish. It depends too much on gatekeepers to help with access, and this often does not work effectively:

You have CMHTs (community mental health teams) and AOTs (assertive outreach teams). They are what it says, they go out to see people – outreach. They go out, but it's not always as good as the theory, because I find myself having to chase people to do things for me. So they're not always reaching out, you're reaching them!

The fear about personal budgets was that the system will be just as bureaucratic and dense. We explained this was not the intention, and personal budgets should be much more transparent, but people have simply not yet experienced it.

Nevertheless, when they heard about the possibilities for personalised support under their control, participants were very positive. As people said, creative solutions to mental health support needs often cost less than conventional services, as well as being under the service user's control and far more effective:

If you actually get a prescription, it's not for tablets costing £3 each that you take three times a day, it's to go to the cinema, or the health club, that's a fiver – that's actually costing less money.

Confusions about personalisation

Some participants in the four groups we ran had a degree of knowledge about the personalisation agenda, having attended previous meetings, or in some cases, having taken part in consultations.

However, in many places, there is still considerable confusion about what personal (or individual) budgets could be. At best, they are seen as a type of direct payment, rather than an overarching system for self-directed support. The word 'budget' is taken as synonymous with 'payment', and the

chief concerns are often about referral routes, and eligibility barriers. People are concerned that personal budgets are yet another new system, imposed on top of the direct payments system.

Participants in all groups were well aware of the support needed both to access and to manage a direct payment, and felt they would also need support with personal budgets. Particular barriers were mentioned for people who have recovered sufficiently not to have services, and are no longer in touch with a care coordinator. Participants felt it was vital to get the process of personal budgets right, so they could start to think more clearly about options relating to their individual support needs.

Will personalisation work?

When the basic principles of a personalised system were explained, people in all four groups were very positive about the ideas. People are particularly enthusiastic about the underlying principle of choice and control lying in the hands of the service user. However, they often mentioned other people with mental health needs who would not be safe in using a direct payment, and who may need help in case they misused the money. In one group, a member had known someone who had a direct payment, but could not manage it well:

They need someone to help them manage it as well. But it wasn't factored into the way they got the money.

Participants discussed the kinds of safeguards that need to be in place, so people with mental health needs can manage risk for themselves, and have choice and control in a safe environment. Their own ideas about solutions and ways forward are listed briefly below.

Service users' recommendations for the personalisation agenda

Quality of the care coordinator or other supporter

When people got good support, they said it was largely because of the individual care coordinator or supporter. They said it is important to be able to trust the professional, and for the care coordinator to treat the service user with respect. One person described a care coordinator she trusts:

Well he believes me, he respects me, and he really is trying to help me.

One of the worries about personal budgets is the possibility of losing the already meagre contact people have with these professionals. If personal budgets are going to work, then people felt this would depend on the key players respecting and showing belief in service users.

A streamlined system

Some people had experienced the bureaucracy involved in accessing direct payments and felt personal budgets need to be far simpler, and more streamlined. In particular, one group talked about the importance of having open, transparent information about the ways in which different areas work. This followed a discussion about different localities implementing personal budgets in different ways:

What we need is... a chart – some people like charts – about how they can access their budgets. And what are the consequences of budgets, how they're going to be appropriated, the legalities of these budgets.

Participants were aware that providers of services also need to understand about personalisation. Unfortunately, those who had been involved in implementation meetings about personal budgets felt confusions and complications had already set in:

We are having meetings at borough level with regard to these budgets, and to me it is not as simple as direct payments, it's more complicated.

Support and brokerage

People in the focus groups were aware they would need support in order to develop their own plans, and also to assess and monitor how things are going:

That's where you need support to assess whether that thing is helping you, or somebody's taking advantage of you because you're feeling quite vulnerable, because it does happen, very easily. I've seen it, a lot.

This theme was not developed further, and would benefit from more exploration.

A passive list

As mentioned above, fluctuating needs are a major issue for service users themselves. A personal budget should therefore not be fixed and rigid, with a set amount of money or support each week. Participants said the allocation of a personal budget should be capable of being used as and when needed. People in one group suggested keeping people on a 'passive' list in case their needs fluctuate:

People should remain in the system, even if they're not actually needing care at that time. They should be on the books, so you can get a care coordinator.

Information and education for service users

There was much confusion and misunderstanding about the implementation of personal budgets. One group talked in particular about the need for more training and information. They felt service users themselves need to be geared up and ready for the changes. In fact, they said the focus group itself had been a start, but needed to be followed up.

We should get people to come and educate us... As far as the system's concerned, we do parties here, and that could support people with these mentors to give them guidance, so they can get to learn certain issues, because people are in the dark about certain things.

4. Identity and aspirations

- The goals people with mental health problems have in their lives are the same as anyone else would have.
- People want meaningful activities, friends and close relationships.
- Confidence and motivation are key.
- Participants are proud of their identity as mental health survivors.

Ordinary goals

The people we met in the four groups told us about goals and aspirations that are just like those anyone might have. They want to have fulfilled lives, find meaningful activities, have friends, socialise and enjoy close relationships and security. These are the same things everyone wants, but which may sometimes be difficult to obtain within the 'mental health system'.

A personalised approach to care may free people from stereotypes attached to traditional services. Participants generally did not talk about their 'needs', nor did they think in terms of services. In fact, in two groups, people mentioned that formal mental health services often carry a stigma, which can hold people back:

If you were motivated to go to a job interview yourself, sometimes you would not be asked about your mental health problem, it depends. But if you do it through Links, your mental health issues may be divulged. And with employers, you've got all these issues.

Personalised support services can help people access ordinary activities, which they currently find difficult to access. A personal budget was seen not always as a way of funding ordinary activity but as a means of accessing support to give confidence or an extra push with motivation, in order to keep up a regular commitment. For instance, in one group a man talked about a local rambling association, which he enjoyed very much. He said rambling is a

good physical activity, keeps him fit, and helps him remain stable. However, in order to do something like this, he may need transport assistance to get there, and a personal budget could cover that cost.

Transition from 'mental distress' to community life

Personal budgets can be particularly useful when people leave hospital, to provide more flexible support. Participants felt the transition from hospital back into the community was a crucial period of time, in which people can easily become unwell again. At this point, above all others, people said they need a safety net. Support should include information about what is available, and continued offers of support, even if 'well' at that point in time. Participants in one group said personal budgets should allow you to pick up support flexibly, when needed:

People that have been discharged still have needs, and without support they can crash again, so it's actually finding a way of direct payments, or individual budgets could plug that gap...

You feel a bit safer that you can sleep at night, and know that there's that bit of security there for you.

You've missed out a big gap out of your life. It's like you're in a box. You don't see what's outside that box for a period of time, so you need regenerating and building up.

People talked about the problems of becoming reliant on medical expertise, and the consequent difficulties in pursuing their own lives afterwards. For instance, people talked about problems in building relationships, and problems in how they 'come across' to other people. A common issue people experienced was isolation.

Participants said social workers and other care coordinators cannot fulfil this need on their own. Access to activities that promote social inclusion

and build up social networks and confidence is needed. A personalised approach will rely less on care professionals and more on integrating support into daily life.

That is not to say care professionals will become redundant within a personalised approach. Care coordinators still have many roles, one of which will be to enable and facilitate ordinary activities in the community, and to help educate local communities to ensure better understanding of the needs of those who have used mental health services.

Confidence and motivation

Having a personal budget and being in control of the support you need is seen as an important factor in building confidence and motivation. People associate mental distress with loss of confidence, and the problems of keeping up motivation when unwell. Therefore the key they saw to getting good support was often about having “activities to build confidence”.

In one group, there was some agreement that support from the family is important, and a carer who was present in one of the groups said she feels central in keeping up her daughter’s motivation to get out and do things. In another group, a participant mentioned that her need for support in the winter months increases, since her motivation wanes at that time, and at this point extra sources of support are useful.

Motivation, however, is not necessarily something that requires service supports. It is mainly about other people, and there was some discussion about the difference between community life and ‘service’ or hospital life. People in one group said motivation chiefly comes from having models around you, and people who are doing things you might want to do.

However, comparing your own life with those of friends may not always be helpful, and people said you do need to be well enough to maintain your motivation and focus. In particular, they said it is hard to get anything out of activities, socialising or work when you’re ill, since concentration is impossible. The big issue here is the fact that people’s conditions fluctuate, and that both confidence and motivation can grow at times, but disappear at others. People therefore want support that will be under their own control, to call on

when they need it. The essential element of this is to be in charge of planning their own support.

Remaining well

It is vital that personal budgets take account of the fluctuation in many people’s lives. Since people’s needs can fluctuate, participants said problems often arise when the support stops.

When the social worker stopped, then the funding stopped, and I was left very much alone and I had to rely on my disability living allowance. And it was very hard. I’ve had to organise myself, and I’ve found that the stress has caused quite symptomatic – my health has not been too bad, but it’s not as good as it could be.

This was described as a see-saw, in which people manage fine with support, get better, and then lose their support and went downhill. By contrast, people in one group talked about the need to have support when well, so you stay well. They said it was important that people frame their needs as ongoing, saying “I have mental health problems, although I’m better at the moment”. Again, this was seen as an important role for personal budgets, since they can constitute a ‘safety net’. This would involve having minimal support under the control of the individual to call on as needed:

[People are] left in limbo until they crack, and that’s why they need that money, so they can use it to get someone in, even just to step in for five minutes so they can air their views.

Positive identity as a mental health service user

When we asked participants in the groups about their goals and aspirations in life, many people said their goals and outlook on life have changed since they have experienced mental health problems. This result was not always negative, and several participants said their experience has made them stronger and their lives, perceptions and goals are now more balanced and satisfying than before:

Well I think when you’ve gone through an illness, your goals in life actually change a lot, but not necessarily for the worse.

The idea of a ‘positive identity’ came up in every group, with one person talking about his role as an

activist, another who attends planning meetings for services and several who are involved with the running of their local Mind association. All these roles give people a new feeling about what they can contribute, and a new way of thinking about themselves. In one group, people shared ideas about a website they access, which helped them build a positive self-image:

I used to think of it as normal, but now I think – I'm just as happy now as I was before, but in a different way really. I find that I'm doing things that I like doing now, with my time. It

takes a while to get to that stage, it didn't happen overnight.

In terms of personalisation, people felt their support services should not rely on a passive, illness model. When they need support, they do not want at the same time to lose their sense of a positive identity. This is precisely what personal budgets can give them. One person summed this up memorably:

In the fight to be free to be who you really are... what you're seeking is, like, a lovely life.

5. Ideas about using personal budgets

- People have creative ideas about how they would use a personal budget to live independently, support social relationships, or go out.
- Independent travel and paying for social activities are both key needs.
- Personal budgets can contribute to the cost of computer use, skills or technical support.
- Personal budgets can contribute towards holidays and breaks to support mental wellbeing, and provide opportunities to keep physically fit.
- Personal budgets can support people to access learning, and to take part in volunteer activities, as well as paid work.
- Group activities are also important, and many participants talked about keeping up peer support.

Having presented the key messages about what people want from the process of personalised support, we now turn to the specific ideas they mentioned about how personal budgets might help them in their own lives. The ideas that came up in the different groups are all individual to particular needs and interests. However, there are many common themes, and they are grouped here under headings related to the goals in people's lives.

Having your own place to live

Having your own place to live was something people very much value, and those who did live in their own flat or house were adamant that they want to maintain their independence. By contrast, being 'cared for' was seen as something very restrictive. In order to carry on living independently, people said they could use a personal budget to buy in the PA support to help with budgeting, to

have general support at home, and to have a personal assistant who would help with domestic activities, making them more enjoyable and effective.

If I had a personalised budget, I could actually pay for my own accommodation support, that'd be so much better.

An interesting point that came up in one group was that people can benefit from learning how to do their own home decoration. A personal budget could pay for materials, as well as personal support to learn and do DIY. They felt this would have many pay-offs, as the home environment can help people's mood and general wellbeing:

So that could be something which could brighten up somebody's home situation. Either help to do it, or money for the materials.

Going out

Personal assistants are often associated with direct payments and personal budgets. Although PAs were not the only focus of the discussions we had, some participants said a PA could help them get out and do ordinary things, like shopping. In some cases, people said they needed the kind of PA who would help set boundaries, so the PA sometimes needed to be a "bit tough".

But I'd like someone to go shopping with me, my life would be so much better to have that kind of assistance.

Talking over problems

The point about having a PA is not just about the functional value – eg, getting the shopping in. A PA also provides human interaction. The quality of personal assistance was important to people, and especially the issue of a trusting relationship. This particularly applied when people were aware they needed someone to insist on boundaries.

To advise you, and just to have a mentor to talk to, not like a counsellor, but just in case you

have any health problems. My father's just had an operation – and it'd be nice to have someone to talk to, like a support network.

Once a relationship has built up with a PA, there is an element of friendship and trust. A PA is someone to talk to, someone just to 'be there'. People said they want PAs as a type of multi-purpose support. One person mentioned 'befriending', and many people said they'd like to employ PAs who keep them company.

In two different groups, people talked about the actual activities they could undertake with the PA. In this sense, PAs are seen very much as equals, people who can share interests with the person they support, and can join in and enjoy things together. One person had joined a stained glass course, and wanted to go along with a PA who has a similar interest and skills. Another person said she would like to go out to London, and do shopping together with a PA. In all these ways, personal budgets can help people achieve key mental health outcomes, through the support of personal assistance.

Travelling independently

In order to get out of the house, and to pursue activities or meet other people, transport is often necessary. For some people, public transport causes extreme anxiety, and one person said she has to have assistance in order to go on the local bus. For many people the problems are exacerbated by living in a rural location.

Those who do use public transport said it can be quite worrying, and they feel isolated or panicky if they have to catch the last train back. Even catching the local bus in the morning can add to people's anxiety, and cause them to miss appointments or fail to turn up at work.

Some of the ideas for using personal budgets related to independent car travel. For two people, this meant learning how to drive, and using a budget to help pay towards driving lessons. Another person suggested they could pool budgets to fund a 'safe driving' club, where people could learn and get confident in driving. Even for those who had a driving licence, there are problems in keeping up a car, both financial and relating to car maintenance skills. A personal budget could be used to help learn these skills, or to hire someone in for regular car maintenance.

Keeping up connections with other people

A personalised approach to mental health support should recognise that social connectedness is one of the keys to good outcomes for service users. In all the groups, people talked about the importance of meeting others. This was often about ordinary opportunities to socialise, but some people said it was difficult to keep up these ordinary events when they had lost confidence. Therefore, having a personal assistant might help in enabling people to get out and meet their friends.

More often, though, it was a combination of financial constraints, lack of social contacts, and loss of confidence that stopped people having a social life. In one group, people talked a lot about the example on the Yorkshire and Humberside DVD about a woman who bought a dog with her direct payment. Walking the dog could be a good way to meet other people.

Social connections are crucially important, and were mentioned in several different contexts. In particular, the points below about computer use, and also about pooling personal budgets, relate closely to the goal of communication and mutual support between friends.

Developing and keeping up personal relationships

Keeping up close relationships is vital to mental health. In one group, this came up in the context of needing support to actually establish a relationship, see each other regularly and have joint activities. The person who brought this up said they would need a PA whom they could really trust, and who would be able to manage the support role very sensitively.

Many people mentioned the fact that their family members have moved away, and they are no longer able to see them on a regular basis. This can cause some distress, and by contrast, one person said when he does see a family member, this really helps his mood:

It's like when you see your daughter it lifts your spirits. That's a family thing.

A personal budget could be used in different ways to support people to see family members. People

suggested a PA could help someone travel to see their son or daughter, or in fact they could get help towards the transport costs. In one case, a group member talked about the support and security her parents had always given her. Her father had now moved to Spain, and so it was far more difficult and costly to go and visit. Nevertheless, visiting her father was exactly the type of 'short break' she needs, and it helps with her mental health. She said a personal budget could help her plan in regular trips abroad for family breaks.

Despite the importance of family and close relationships in providing support, there were other occasions when people mentioned family problems. One person suggested using a personal budget to "educate the in-laws", who do not always understand mental health issues. Another person mentioned how difficult it is to keep up the parental role. A personal budget could be used to help a parent with the tasks they need to do for their children, having someone to visit the home to help with homework, with preparing meals, or even helping children to get up and go to school.

Internet use

Having a computer clearly opens up opportunities at many levels, and can give good support to people with mental health needs. There was discussion in all of the groups about how personal budgets could support people to use computers. In the main, people saw internet use as a way of keeping up social contacts (through email or message boards), obtaining information and getting social support:

It can be a good sense of social support, I go on the internet a lot... I sort of use it and it helps me out information-wise, and entertainment-wise.

If you've got a computer, at least you can send a message to your friend... so you're making connections, you're building a bridge.

In two of the groups, people discussed the possibility of using personal budgets towards enabling computer use. Individuals might pay for internet access, or technical back-up for computer maintenance at home. Some people may not have a computer, and would benefit from using a personal budget simply to buy one and set it up.

Other people mentioned courses in IT skills, and particularly the type of support course where

individuals could learn at their own pace. A personal budget could be used towards paying the course fees, or indeed having ongoing support in learning skills for internet use. One person mentioned that computer use was absolutely vital for her, since she was dyslexic, and another group mentioned a computer club. They discussed how personal budgets could be used to contribute towards a club, where computers could be 'bought up cheaply' and volunteers could help set them up.

Having a holiday or a short break

Holidays or short breaks were also felt to be an important way of maintaining mental health and tackling mental distress. People said holidays are vital for their mental health, and something that is not always possible to factor in to a limited budget. Personal budgets could be used to pay for assistance in order to go on holiday, or to organise a break.

Several people had experience of group holidays and organised trips, and there were mixed opinions on those. In one group, members were very keen to keep up the opportunities they had had for group outings, and spoke enthusiastically about trips to the seaside or to the countryside. They said they would want to pool personal budgets to keep up these opportunities. Another person, however, had had experiences that were not so positive:

But it's not everyone's cup of tea, going away with a lot of sick people. And if you have to share a bedroom with one of them, that can exacerbate your problems.

Studying and learning

In every single group, achievement of educational goals came up several times, including degree-level qualifications, art courses, IT and other more general courses. Within a personalised mental health system, many participants will take up more opportunities for learning, which will help them to achieve mental health outcomes.

In most cases, people said they already have experience of studying, and want to go on to achieve further qualifications. For instance, one participant was completing an access course, and wants to go on to a degree course at university. Another participant talked about a textile course she would like to do, both to gain confidence and

also to gain skills and qualifications for the future and for her CV. A personal budget could be used to pay for the course itself, and also possibly for someone to help her get to the course. Another person mentioned a Masters course she would like to enrol for. A personal budget could help contribute towards materials and books for this course, which would really help her.

In general, education and study are seen as ways of 'pushing yourself' and keeping busy, as well as valuable opportunities to gain qualifications. More than that, they are seen as potential social opportunities and ways of getting out and meeting people, and thus address mental health needs and outcomes in many ways. A large barrier people faced was the problem of keeping up motivation on a regular basis:

Some mornings I've literally got to pull myself out of bed, because I'm so heavily sedated. In the summer it's not so bad, because it's bright and sunny outside, but in the winter when it's cold [I] don't want to get up.

The ways in which a personal budget could help to overcome this barrier included having a taxi in the winter months to get to college, or providing additional support. This could be either a PA to come to the course with the individual, or someone outside the course to go over material and help with study at home.

Several people who came to the focus groups had roles as advocates, activists or volunteers. Specific training courses could help them in their roles. One person mentioned a certificate in advocacy, for instance. Others talked about specific courses they would like to develop, almost as a group project. In one group, people suggested personal budgets could help to buy in a facilitator or a tutor to help them with drama:

It's the different category of acting, it's how you portray yourself...this money they're giving us now, could bring a drama teacher, to teach us drama, so we can learn to express ourselves.

Working and volunteering

Personal budgets can be a very good way of providing flexible support for employment, and the goal of contributing to society was very important within our group discussions. More than one person had a part-time job, and feels this is very

valuable. Participants suggested a personal budget could be used for support both to get a job and to keep a job (eg, a PA to go into the workplace with you, someone to help you manage work tasks and keep a written record of what you need to do, or a job coach to keep up contact with you after you've started a job). These are all supports that could be covered by Access to Work funding, and the fact they are mentioned here indicates that personal budgets may be required to fill a gap in support for people who enter part-time work, or require more flexible or longer-term support.

However, paid work is not always felt to be the only desirable goal, and in one group in particular, there was an interesting discussion about work and the changing nature of the 'work scene' in the current recession. People talked about the pressure to work, and the societal push to get a job, which could impact negatively. It was also felt keeping up paid work depends on the current state of your mental health, and this creates difficulties for many people.

It depends on how well you are at the time. Some people might be going, 'I want to get a job', other people might be wanting to get out of bed. It could be anywhere on that spectrum.

By contrast, the focus group participants mostly said they themselves prefer voluntary work, part-time jobs, and having a variety of activities during the week. On the whole, the key to this was 'enjoyment'. Many people mentioned opportunities for volunteering, and felt volunteering should be valued in the same way as paid work. It was often fulfilling for people, and enabled people to contribute to society.

[Volunteering] keeps me motivated. I was on drugs for 12 years of my life. I'm off drugs now... And I helped to do the caravan and stuff, and I'll do any jobs, any jobs, me. What keeps me happy, motivated, off the drugs and getting my life in order.

In another group, someone mentioned a volunteer role he had in supporting others with mental health needs to take part in a walking club. He needed help to set this up, to carry out risk assessments, and someone to be a mentor for him to keep up this role. In all these ways, a personal budget can help to support people in managing volunteer roles.

Other people talked about particular plans they had for managing their own lives, and for contributing to society. In some cases, a personal budget could help them set up their own business, or turn a volunteer scheme into a work opportunity.

One person had attended a women's group for a long while, which was staffed and supported by volunteers. A facilitator had managed to change this, so service users could themselves carry out the work needed to provide refreshments and run the group:

I'd been going there from the women's group for about 14 years, then when Jane came in, she said to employ people there instead of having just voluntary workers. She said she was sure we could do tea, coffee and sandwiches and do the food hygiene certificate.

With creative thinking, people said a personal budget could help them with a set-up grant or some business advice, and enable them to turn volunteering or 'service' provision into business opportunities.

Keeping up physical fitness

Physical fitness was seen as a particular goal by many people in the focus groups, who feel these activities can contribute to achieving better mental health.

Two people mentioned using a personal budget to buy membership of a local gym, several people talked about a rambling club, and others discussed the possibility of taking up cycling. A personal budget would be useful not only to buy a bike, but also to become confident in riding it on the road. Some members had previous experience of a cycling club, where they had learnt how to ride and to maintain their bikes. This was something which they felt would be valuable to keep up through a personal budget.

In more than one group, people also talked about the negative impact mental distress can have on physical health. In particular, the effects of medication can mean unwanted weight gain, and so activities geared towards combating this are valuable:

I've put on 60 kilos since I started on the medication. If the exercise bike – now I would

go on that, if I could afford an exercise bike then I would use that, and I could keep the weight down... For me, a very good pair of shoes is a good thing, like you can walk in, like good running shoes, for support.

A personal budget could be used to buy the exercise bike or the equipment you need to get fit. However, it could also be used to get support for keeping up fitness activities. People were aware that 'if you're on medication, you don't always feel like exercising, because you feel tired', and it could help to have a PA to encourage you to go walking, and provide company when out walking or running. Another person said she would use a personal budget to go to a Weight Watchers group, and yet another talked about a healthy eating course, and using a computer to find recipes which she could manage herself. The area of physical fitness was one in which personal budgets can be deployed very creatively, in seemingly straightforward and simple ways, and achieve important benefits for people's lives.

Directly tackling mental health distress

All the ideas mentioned above for using personal budgets relate in different ways to supporting people to keep well, tackle mental health issues, and deal with potential mental health problems. They are about 'recovery', and leading an ordinary life with ordinary goals, despite ongoing mental health needs. However, a few things suggestions were more explicitly directed towards dealing with mental health issues.

One group mentioned the possibility of buying in counselling support with a personal budget, and another person suggested they could use a personal budget for massage. One person said he would choose hypnotherapy, and people agreed alternative therapies can be very useful on an individual basis, even if the evidence shows they do not make any physical difference. They still feel it was valuable to have the choice, and being in control of your own path to recovery is in itself valuable:

You can get drawn into this little therapeutic world, that everyone subscribes to... And also they can take advantage of you if you're a bit vulnerable, thinking there's this magic, fix-it, guru person out there, who's going to do it for

you. And they're not; you've got to do it yourself.

Being part of a group and getting mutual support

Just because people are entitled to choice and control over the way they meet their own personal needs, this should not mean losing group support or valuable services. Indeed, people can choose to have a group service as part of their individually designed support plan. The final message from our focus groups is that personalisation should not destroy the possibility of peer support and group activities. Participants talked about pooling budgets, in order to fund group activities, mutual ventures or peer support. Particularly because the focus groups were taking place in local Mind associations, many of the participants already benefited from strong group structures, services and activities provided by Mind.

In many cases, participants feel they themselves were a part of the provision, and they act as volunteers within their local Mind associations. One person is a trustee, others volunteer to support new members, and one group has a café run by members. Many people echoed the sentiment expressed in the following remarks:

I think the volunteers here seem to be like a big family, don't they?

Coming to Mind, helping the staff. It makes me feel good, it makes me feel better. I know I'm safe here, I know I'm looked after, I know people will listen to me.

There was a strong feeling that individual choices should not result in isolation, and many people said they also want group services to be available. Indeed, the focus groups themselves are evidence of the enjoyment people have in meeting with others and sharing their experiences. People suggested in one group that they could pool their personal budgets in order to fund a peer support group; in another, a poetry-writing group and perhaps also to go on holidays together.

As self-directed support becomes more readily 'on offer' throughout the country, provider organisations will have to learn how this will affect them. As we heard from these focus groups, providers are not going to become less important, but will need to take up new roles, helping people to organise themselves, and supporting peer advocacy. The people we talked to want to work together with providers, to bring about more choice and control for all mental health service users.

6. Afterword

Since the four focus groups for the 'Putting us first' project, other people have contacted us, and we have had input from a panel of service users. There remains much confusion and misunderstanding about the nature of direct payments, let alone the impact of personalisation on the mental health system, and these misunderstandings naturally lead to fear on the part of individual service users. When professionals themselves do not understand the basic facts about personal budgets, it is hard for service users to have the confidence to express what they would really choose for themselves.

Further, we have had contact from a creative arts project, which provides a space, facilities and support for a group of artists with mental health needs to come together on a regular basis. This group, like many other support groups including local Mind association services, is facing problems about its core funding, because people who use the project do not necessarily have 'eligible needs' under the 'Fair Access to Care' (FACS) criteria. It is clear that services, groups and co-operatives that

exist already will need to learn how to respond to the new arrangements for personal budgets, by costing out their services on an individual basis, and by attracting service users who wish to buy in to the group project, whilst preserving the open access policy which so many services feel to be important. This should not be impossible to achieve.

Participants in our focus groups said they wanted a good supportive network to fall back on when necessary, but one that would not control and regulate their lives. A personal budget would enable them to achieve control over their own lives. This in itself is strongly connected with the concept of 'recovery' and the last word on this will be left to a participant in one of the groups:

It's about recovery and self-management. Because your social worker, your support worker, they're not going to be there all the time, so you have to devise a plan that'll help you reach and attain your goals.

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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We are particularly grateful to the service users who gave us the benefit of their expertise, their creative ideas and open-minded suggestions about how they would use personal budgets. We trust the personalisation agenda will progress, so these people can benefit, and have choice and control over the support they need to pursue their goals.

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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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