



National Mental Health
Development Unit

Mental Health Network
NHS CONFEDERATION



Personal health budgets

The views of service users and carers



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The National Mental Health Development Unit

The National Mental Health Development Unit (NMH DU) was launched in April 2009 and closed in March 2011. It provided national support for implementing mental health policy by advising on national and international best practice to improve mental health and mental health services. It consisted of a small central team and range of programmes and was funded by both the Department of Health and the NHS.

The NMH DU commissioned or provided:

- specialist expertise in priority areas of policy and delivery
- effective knowledge transfer in research, evidence and good practice
- translation of national policies into practical deliverables that achieve outcomes
- coordination of national activity to help regional and local implementation.

NMH DU's work was developed in co-production with the Department of Health, the ten strategic health authorities and strategic partnerships with other groups such as the NHS Confederation, the Association of Directors of Adult Social Services (ADASS) and the major mental health third sector organisations.

For more information on our work, see:
www.nmhdu.org.uk

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Executive summary

People who use mental health services want more control of their care, but only a minority would consider taking up a personal health budget.

Completing our suite of studies looking at what key groups in the NHS think of personal health budgets, this report presents the perspective of mental health service users and carers. Based on the views of 60 people who participated in focus groups, and 100 who responded to a survey, we find that the frustrations people currently feel with their care – lack of involvement, poor coordination and over-medicalisation – match many of the things personal health budgets are meant to improve. However, there is scepticism over how effective this policy can be at challenging established clinical and organisational cultures. Participants thought that mental health services would have to first become much more person-centred if personal health budgets were to work. But if this change were to happen, many asked, would personal budgeting still be needed at all?

Almost all the people who participated in our study said that they would choose to change some aspect of their care if they were in control. A significant minority said they would consider taking up a personal health budget in the future to do this, albeit with numerous caveats. Most, however, did not think that they were right for them. For these people, there was considerable uncertainty about the problems and unintended consequences that might arise from taking on such a large degree of autonomy without adequate support.

One of the problems identified in our research was that people found the profusion of terms surrounding personalisation confusing. Despite an initial presentation of the concepts, service users and carers were frustrated by what they perceived as a rapid turnover of policies in this area, and most of all by the complexity created by the separation of social care needs from

health needs – a division that was ‘arbitrary’ in mental health. People who had held personal budgets in the past through their local authority tended to be positive about them, but also felt that they were very complicated.

Asked about how well the services they used currently worked for them, a high level of demand emerged both from service users and carers to be given greater choice, freedom and control of their care. Participants did not feel that their views and ideas were sufficiently taken into account by managers or clinicians and, if given control, most would want to ‘de-medicalise’ their care by seeking more holistic treatments, choosing their own health professionals or changing providers. Most felt that mental health services were too risk averse and wanted to be supported to take more responsibility, including more risk, for their own health.

Despite this dissatisfaction, opinion was divided over whether personal health budgets would be worth taking up, with half saying they would not consider using them and others expressing ambivalence. A major factor for many of those who did not think that personal health budgets were right for them was a scepticism over previous national policies to promote personalisation that had failed to make an impact on their own interactions with clinicians. If they hadn’t listened to me then, it was asked, why would they now?

Of the many people who did support the introduction of personal health budgets, either for themselves or for the benefit of others, this generally came with several caveats, on which we expand on pages 18 to 20.

- The process behind personal health budgets needs to be transparent.
- Their introduction must not lead to valued existing services being closed.
- They must be adaptable to fluctuating needs.

- They must not widen health inequalities.
- Appropriate levels of support must be given at every stage of the process.
- They must be accompanied by a shift in organisational and professional culture towards partnership and supported risk taking.
- They must be aligned with personal budgets in social care and grounded in a broader social understanding of mental health.

Many of the views of the service users and carers we spoke to will be controversial, and are in tension with some of the opinions in our previous clinical and managerial studies. At the end of this report (see page 21) the NHS Confederation gives its viewpoint that a lot of work still needs to be done on this policy if it is to deliver what each group wants from it. The scepticism of service users and carers over the ability of health professionals

to change the way they work reinforces our previous conclusion that NHS staff must be convinced, not coerced, into adopting personal health budgets. This can only be achieved by increasing their involvement in the development of this policy as soon as possible, and by rethinking the role that the Department of Health has given the national evaluation as merely to “inform the further roll out”¹ of personal health budgets.

Perhaps the most significant contribution of this research is that it gives some initial impression of the level of demand for personal health budgets in the NHS. It suggests that they are likely to be attractive to a significant number, but by no means a majority, of eligible patients. This should not be viewed as a limitation of the policy, as it is likely that even a small proportion of personal budget holders would lead to some fundamental shifts occurring in the way that health services are delivered.

The personal health budgets series

This report is our last in a series of reports on personal health budgets. We will shortly be publishing further analysis and reflections on what these reports mean when taken as a whole.

The previous reports in the series are:

Personal health budgets: the shape of things to come?

Shaping personal health budgets: a view from the top

Facing up to the challenge of personal health budgets: the view of frontline professionals.

All the reports can be found at www.nhsconfed.org/publications

Introduction

This report presents the views of mental health service users and carers about personal health budgets. It is based on research undertaken with 162 service users and carers who took part in the study – 58 by participating in focus groups and 104 by responding to an online survey.

This report complements two earlier publications – the first exploring the perspectives of local health and social care leaders², the second focusing on frontline clinicians.³

The main aims of this study were to find out what mental health service users and carers thought about personal health budgets, in particular:

- their usefulness in meeting people's needs
- the level of understanding and awareness about them and personalisation more widely
- what support and information people would need if they were to take up a personal health budget.

It should be noted that the participants in this study were not involved in the ongoing national pilot of personal health budgets and thus had no access to – and limited awareness of – them. The findings are therefore the result of a conceptual research process, whereby service users and carers were presented with facts about the possibilities and processes of personal health budgets and had their responses recorded.

Definition of a personal health budget

We define a personal health budget as the allocation of NHS funding which patients/ service users, after an assessment, are able to personally control and use for the services they choose to support their health needs. It is distinct from a personal budget, which is a similar mechanism already in widespread use by local authorities for social care needs.

A caveat

It is important to note that the views discussed in this report were given in a context where the participants had limited awareness of personal health budgets and little information about the provisions and processes involved. Almost all participants had long associations with mental health and social care services and had seen many policy changes in that time. Their views and opinions are based on this long association and their own specific experiences of interactions with a range of professionals.

Methodology

This study was designed with three distinct phases, incorporating a mix of methods. The initial phase involved interviews with a panel of experts in order to formulate the main research questions and work out how personal health budgets should be explained in a clear and simple way. Following this, a quantitative survey was conducted between October 2010 and January 2011 and a series of qualitative focus groups were held in March 2011.

The survey

The purpose of the survey was to get a broad picture of people's views as well as inform the methodology of the focus groups. It aimed to collect mental health service user and carer views on:

- the usefulness of personal health budgets in meeting people's needs
- what help and support people would need to take up a personal health budget
- if someone was already receiving a personal budget for social care needs, what their experiences of these had been.

Electronic and hard copy versions of the survey were disseminated using a wide range of service user and carer networks, as well as voluntary and community sector organisations. A total of 104 people responded. 72 per cent were mental health service users and 28 per cent were carers. Ten respondents had previously received a personal budget through their local authority.

The focus groups

Six focus groups were conducted in different parts of England:

- FG1: Hereford (carers)
- FG2: Coventry (carers)
- FG3: Leicester (carers, specifically recruited from black and minority ethnic communities)
- FG4: Preston (service users)
- FG5: London (service users)
- FG6: London (service users, specifically recruited from black and minority ethnic communities)

In each region, a partnership was set up with a local organisation to recruit participants and co-facilitate the groups. Participants were sent an information sheet in advance and given time to ask questions about the focus groups. All participants who took part signed a consent form.

To facilitate as informed a discussion as possible, a presentation on personal health budgets was prepared with input from the NMH DU. This presentation was delivered at the start of each group, followed by the focus group discussion.

Given the lack of awareness of personal health budgets, it was not surprising that many participants who signed up for the focus groups saw them as an opportunity to find out more. To maintain the neutrality of the research, specific questions from participants were not answered beyond the facts in the presentation and official information published by the Department of Health.

The focus groups developed further some of the key themes from the survey, including:

- views about choice and control
- information and support issues
- confidence about applying for or challenging decisions about personal health budgets
- views about risk
- key messages for future policy development.

A total of 58 people took part in the focus groups, with an equal number of service users and carers. Five people had previously received a personal budget through their local authority.

Analysis

Focus group discussions were recorded, transcribed and, in one case, translated. The transcripts and qualitative data from the questionnaires were thematically analysed based on a conceptual framework developed from the themes in the focus group schedule and some additional ones that emerged during the research. Key findings from the focus groups and survey were determined by clustering data along this framework.

The findings in this report are intended to be descriptive and indicative of a range of opinions rather than statistically reliable and verifiable outcomes, given the geographic and demographic diversity of participants and the limited knowledge they had about personal health budgets.

Background

Personal health budgets are a cornerstone of government policy to improve the responsiveness and flexibility of health services in England. They are one part of a much broader agenda to 'personalise' the care delivered by the NHS, which includes giving patients more choice and control.

Personal budgeting has been used in social care for several years, including some local authority funded mental health services. Since 1996 English local authorities have had the option to make direct payments to service users. Few did so until a national pilot programme in 2006/7⁴ and the introduction of a national target (N1130) encouraging 30 per cent of social care users to be using a personal budget by March 2011.

The possibility of using personal budgets in the NHS was initially ruled out. However, following the Darzi Review of 2008⁵ a national pilot to test personal health budgets was devised. This pilot began in 2009, with 75 PCTs expressing interest, 20 of which were named sites for in-depth evaluation. The evaluation of the national pilot will release its final report in October 2012.

Although personal health budgets began under the Labour administration, the policy has cross-party support and has been strongly endorsed by the coalition Government since coming to power. The white paper, *Equity and excellence: liberating the NHS*⁶ presented the initiative as having the potential to improve outcomes, transform NHS culture and encourage the integration of health and social care.

In mental health, the new outcomes strategy, *No health without mental health*⁷, provides further evidence of the momentum being given to personal health budgets. It states that the Government will "take steps to extend as much as possible the availability of personal health budgets to people with mental health problems" and that "learning from the evaluation, due to report in October 2012, will inform the further roll out of personal health budgets".

Types of personal health budgets

The Department of Health has identified three ways a personal health budget could operate:

1. **Notional budget.** No money changes hands. The patient/service user is informed how much money is available based on their health needs and talks to their doctor or care manager about the different ways to spend that money.
2. **Real budget held by a third party.** A different organisation or advocate holds the money for the service user, and helps them decide what they need. Together, they can then buy the services they have chosen.
3. **Direct payments.** The service user gets the cash to buy the services they and their doctor or care manager decide that they need. They have to show what they spend it on, but they buy and manage the money and services themselves.

Main findings:

Cutting through the 'service speak'

While there was a general awareness of the personalisation agenda, very little was known about personal health budgets. The distinctions between terms such as self-directed support, personal budgets, personal health budgets and direct payments were a source of confusion, with the greatest frustration being the 'arbitrary' division between health and social care. At the very least, personal health budgets need to have their boundaries defined in a clear and simple way, but they should also be used to challenge the existence of this 'service-centric' system.

Confusion generated by constant change

"Confusing" was a word that was often used by participants when asked about their understanding of personal health budgets. There was considerable uncertainty among service users and carers about what direct payments, personal health budgets, personal budgets, self-directed support and so on are, and on how the criteria for eligibility are determined and how decisions are made.

"I think there's a lot of confusion, it's quite muddy, and if somebody is quite unwell, unless their care coordinator understands it, how can you get the best advice?"

Service user (FG6)

In one focus group, it was only towards the end of the discussion that two carer participants realised that they were in fact recipients of personal budgets. While they were grateful for the respite these had given them, they felt they had very little knowledge about how the money was found and whether they could access this again in the future.

There was also a view that confusion was not only common among those who use services, but also among those who provide them.

"Most [carers] find the multiplicity of such terms bewildering. They now have to get used to the distinction between direct payments for health as separate from those for social care. At a conference, even the experts admitted it was hard to specify where one stops and the other starts."

Carer (survey)

Health need and social care need – a damaging distinction?

One of the key difficulties in understanding personal health budgets was the distinction made between a personal budget for social care needs and a personal health budget for health needs. There was an unanimous view that, for the person using mental health services, this distinction was tenuous and potentially detrimental to them receiving the services they needed to recover. Even professionals often struggled to define the difference between the two systems.

“There is an interminable discussion on what constitutes health or social care spending within personal budgets and personal health budgets. Spending on health may yield positive social outcomes and vice versa. In mental health this relationship is even more complex.”

Service user (survey)

Participants felt that, often in mental health, there was a restrictive definition of ‘health needs’ meaning medication and treatment. One service user shared an incident where a direct payment was taken away from a fellow service user because it was argued by the council that it was for a health need rather than a social care need.

“For us, these distinctions are irrelevant. They are more for the benefit of services.”

Service user (FG5)

An example of what participants saw as a health intervention that was often classified as social care was physical exercise. Three of the six focus groups raised gym membership as a potentially helpful intervention that might be excluded from some personal health budget programmes as it would be interpreted as social care, not health.

Mental health service users and carers would welcome clearer definitions of what constitutes health needs and what constitutes social care needs. Ideally, these would be based on the experiences and perspectives of people who use services.

“With the new emphasis on prevention, the meaning of ‘health’ in the context of direct payments might usefully be thought of as being any contribution that would be intended to have as its outcome an improvement in well-being.”

Carer (survey)

However, what service users and carers would really like to see is continuity in care, with health, social care and the voluntary and community sector working together from a single care plan and process.

The thirst for change

Due to the confusion over terminology, it was important to understand the satisfaction and frustrations of service users and carers around their current services before discussing the practicalities of how personal health budgets might be able to help. This chapter details the high level of demand from service users and carers to be given greater choice, freedom and control of their care. It highlights the frustration people feel at not being listened to by clinicians and managers, and an undercurrent of scepticism about the capacity of the system to change.

Unheard and under-involved

There was unanimous support for the objectives behind personalisation and personal health budgets. All participants agreed that people were not currently being given sufficient choice and control of the care they receive, and that service users, carers and service providers needed to work more closely together to develop care plans.

“In its broadest sense of vision, [personalisation] could be fantastic, because you are not saying to people they have to do things a certain way. You’re actually valuing the individual’s perception.”

Carer (FG3)

A common theme in both the survey and focus groups was that people felt neither managers nor professionals were listening to their views. Consequently, many spoke about how the services they were currently given were not always right for them and failed to take into account what they thought would help them to recover most.

“Sometimes when I’m offered services they’re not really relevant to me or what I feel would help me get better, such as going to a day centre. Sometimes they say, ‘these are the only day centres that are available’, and I don’t like it there or I feel it’s not relevant.”

Service user (FG5)

There was a widely-held view that neither carers nor service users were sufficiently involved by professionals in making important treatment decisions. People wanted to have the benefits and drawbacks of various options explained to them and then be invited to give a view, whereas currently they are often prevented from this by not having enough information on which to decide, or by not being asked.

“Mostly psychiatrists will say ‘your son has to be on this medication or that medication’ and then you go and force him take his medication. That’s not choice for me. But if the psychiatrist said ‘look, medication will help in this way and this way, it will not help in this way and this way, and for your son’s issues counselling might do this and something else might do this, so what do you want to do?’ That would look like choice to me and to my son, wouldn’t it?”

Carer (FG2)

The poor continuity of care some participants experienced with their professionals was a significant source of frustration, and was thought to be preventing the development of effective partnerships where the person's needs and personal circumstances were understood. Many carers and service users did not feel that they had a professional whom they could talk to about their overall package of care. Some had no named community psychiatric nurse (CPN) or social worker, despite concerted efforts by some participants to get one.

"I have been accessing child and adolescent mental health services for many years and now adult mental health services. I'm still on the books but I have never had a social worker and right now I don't have a CPN or a key worker. This is now my fourth psychiatrist, I never seem to be able to keep the same doctor. Never, never, it's always somebody different, every time I go."

Service user (FG4)

Doubtful of change

In discussions about how services might begin to listen and respond better, a sceptical tone pervaded many of the conversations. Participants thought that the shift in culture required to make truly personalised services a reality would be extremely difficult to achieve. Control of care, people felt, was with the professionals and they were unlikely to relinquish it.

Several participants narrated experiences where professionals, including psychiatrists, had disregarded their views about medication, accessing non-medical therapies, or about deciding on social activities that might be beneficial to them. If they didn't listen then, it was asked, why would they now?

The ability of national policy to create more responsive services to user and carer needs was viewed with similar cynicism, though it was hoped that it could. An example that was often raised was the Care Plan Approach. In theory, this means service users should be consulted about what they think of their care and involved in producing a jointly agreed care plan between themselves and the care team with input from carers and others. For many people, however, this had not felt like a genuine exercise and they were unconvinced that a care plan in conjunction with a personal health budget would be much different.

"If I ask my social worker he would just say 'are you crazy?' He would deny the right to personalisation, he would deny me the right to assert myself, he would deny me the right to services, he would deny me everything."

Service user (FG6)

Many participants did not see how having a personal health budget would make a difference to their care if the culture of mental health services continued to be non-participatory and coercive. If clinicians and managers did transform the way they practised in this way, it was questioned whether personal health budgets would still be needed.

What difference might personal health budgets make?

Almost all participants said that if they were given control of their care they would change some aspect of it. For most, the big changes they would want to drive would be to de-medicalise the services they received and to make their relationship with professionals and providers less authoritarian. Despite wanting change, only a minority would consider taking up a personal health budget.

If service users and carers had control...

The focus group participants were asked whether they would make any changes to the type of treatment they receive. Almost all participants said that they would. This was based on the view that mental health services remained highly medicalised and needed to adopt a broader, social model of care.

“I’d go from my medication to more holistic treatment, so tap into other things that might help me, save popping pills every five minutes, because that’s all they do. You’ve got this symptom, you take this drug. You’ve got that symptom, you take the other drug.”

Service user (FG4)

The most common changes that people said they would like to make to their treatment included:

- reducing or giving up their medication
- exploring complementary therapies, for example hypnosis, acupuncture and yoga
- increasing social and self-improvement activities, such as education and vocational courses.

Only a few people said that they would not want to change their current services. This was because they either felt that the treatment they currently received was keeping them stable, or because, although they were not satisfied with it, they did not feel they had enough information about alternatives to look elsewhere.

The focus group participants were also asked whether they would change their service providers if they had the choice. Participants acknowledged that there are many dedicated frontline professionals doing their best in stressful and often under-resourced circumstances. But they felt that the culture of service provision remained “authoritarian”, with few instances of real partnership working. Although carers were more mixed in their view, the service user groups agreed unanimously that they would seek to change providers if they were offered the choice. This would either mean switching the individual professionals that they currently worked with (“fire my psychiatrist” as one put it), opting for a completely different care team or looking to receive more provision from the voluntary sector – particularly peer-led services.

Black and minority ethnic (BME) participants expressed their desire to receive more culturally appropriate services based on their own communities rather than mainstream providers. It was frustrating to them that, although not satisfied with the services currently offered to them, they did not know where to go to find information about alternatives.

Mixed appeal

Some participants were enthusiastic about the potential of personal health budgets to help them overcome the frustrations expressed in the previous chapter and access the kinds of services they wanted.

“I would be very, very pleased to use it myself, you know, in whatever way, because I do think that there are other things out there that could help us, and also for my son. If he was eligible, yes, I’d like him to have the chance of having any kind of therapy actually.”

Carer (FG1)

Overall, opinion from the focus groups on whether personal health budgets would be worth having was divided. About half said that they would not consider taking one up, with some categorically saying no and others expressing ambivalence. Of those who said that they would consider using personal health budgets, this came with various caveats about the way they should be run.

- They would need to see a genuine shift in organisational practices and professional attitudes towards partnership working with service users and their carers.
- The medical model of mental health would have to become less central, and be balanced with increased acceptance of a holistic, social model.
- They would need more help and signposting to services. It should be remembered that some participants had no named professional.

- Targeted support for BME communities, many of whom find communication with mental health professionals problematic.
- The NHS, social services, voluntary and user/ carer organisations would need to work more closely together.

Of the 12 survey respondents who had experience of using personal budgets for social care, experiences tended to be positive and this influenced them to be more open to the possibility of personal health budgets. Where there was dissatisfaction with personal budgets, this was linked with people feeling that they had too little support in managing them or not enough information.

Balancing risk and freedom

Service users and carers felt that there were dangers involved in accessing personal health budgets, because having choice and control naturally brought with it risks and additional responsibilities. While there would be a need for much better information and assistance for people to manage these risks, most participants thought that they could cope.

Having choice involves risks

Many participants who showed interest in accessing a personal health budget had concerns about the additional risks that this might expose them to, particularly if it was in the form of a direct payment.

For some, the fear was that if the choices they made turned out not to work it would be seen as a failure of their capacity, rather than them not having sufficient information and support or just trying new things. Others were worried about the possibility that, because of a lack of budget management skills, they might inadvertently mismanage or misspend the money allocated to fund their care. There was a real fear over how they might be dealt with in the event of a mistake, such as having their budget taken away or being “hailed over the coals”.

While participants wanted to have these concerns considered and addressed, they also felt that without being allowed to take more risks they would never achieve the level of improved health they aspire to. People welcomed the opportunity to be in control provided they had the right level of support and guidance. For personal health budgets to have this effect there would need to be a significant cultural shift in mental health services from risk aversion to supported risk taking.

“You can make mistakes, but how else do you find out what is better or worse? Mistakes could happen with anyone if they make the wrong choice, even if they haven’t got mental health problems.”

Carer (FG1)

Enabling and restricting choice

This challenge of managing a greater degree of risk in mental health services was discussed at length by many of the focus groups, who were particularly keen to explore the paradox of free, versus restricted, choice that personal health budgets highlighted. Participants felt that for choice to be genuine they needed to have the available options outlined and explained to them – a menu to choose from.

“You have to be shown what your choices are, as people don’t know. You go into a supermarket and you can see what’s there. But something like this... if you said to my mum ‘you have a choice’, she wouldn’t know.”

Carer (FG3)

However, others thought that a menu also makes choice restricted, as it makes the budget holder dependent on whoever selects the available options for them to choose between.

“They will have criteria and they’ll have a budget. They’ll say ‘right, these are the criteria and you’ve got to go within them. You’ve got your choice but you’ve got to go within these constraints.’ That’s what they’ll do, I know they will.”

Service user (FG4)

No clear consensus emerged over how to resolve this tension, but it reinforced participants’ view that when offered ‘control’ of their services they were not to be alone. “I’m not the doctor” was a phrase often repeated in groups to indicate that real choice could only happen with information and the support of professionals. The concept of the “triangle of care”⁸ – an equal alliance between service user, professional and carer – was helpful in expressing the kind of partnership that participants sought.

What information do service users and carers need?

The number of questions and concerns raised by service users and carers highlights the need for a hands-on, participative approach to disseminating information about personal health budgets. When planning this activity, NHS organisations should make sure they address the following issues that were raised most frequently during our research:

- how personal health budgets differ from and align with personal budgets in social care
- how a service or professional distinguishes a health need from a social care need
- how eligibility criteria are determined, and who makes decisions in the application, assessment and resource allocation processes
- how to challenge decisions made during this process, and the support that is available to do this
- how users and carers have been involved in shaping the assessment procedure, and how to get involved in this
- what services personal health budgets can be used to purchase
- who to approach to make a request for personal health budgets, including in cases where there is no key professional
- examples of how other people in similar circumstances have used their personal health budgets.

Concerns and recommendations from service users and carers

Perhaps the most conspicuous question that arises from this study is why, given the clear demand from participants to have more control, so few say they would consider taking up a personal health budget.

One explanation is the scepticism over how this policy will be able to change deeply engrained clinical, organisational and managerial cultures. Mental health services that listened and responded to users would have to come first for personal health budgets to work, it was thought. Yet if that change was achieved and service users and carers became full partners in their care, what more would becoming a budget holder be able to offer?

There were many other concerns from participants that tempered their enthusiasm for personal health budgets – both for themselves and mental health services more generally. The following seven statements summarise the most common of these and highlight where our research suggests the need for reassurance is greatest.

1. The process behind personal health budgets needs to be transparent

The importance of information to support choice of treatment and provider has been highlighted throughout this report. Participants were also clear of the need for information about how assessment, eligibility and budget calculation

“Information is a key thing. We will need to know – if we are to use this opportunity which, as many people said, is actually quite a positive opportunity – who’s making the decision, what are the criteria for making those decisions; the who and how of decision-making. How are they involving us in setting these up?”

Service user (FG6)

decisions are made. They would also need to know how to challenge these decisions if they disagreed.

Some focus group participants had experiences of their requests for direct payments or personal budgets rejected, with little explanation given. One service user said their professional had refused outright, stating they did not believe in them.

“Mostly what happens with any service is they just tell you that ‘no, you can’t have it’ or ‘you didn’t meet the criteria’.”

Service user (FG4)

There was significant concern among both service users and carers about the psychological effect that rejection experiences such as these could have on people with mental health needs.

“By delaying the self-directed support process both my physical and mental well-being suffered as I was left without support or direction in life. It is now going to take time to rebuild my confidence before I can consider moving forward with my life.”

Service user (survey)

In order to safeguard service users against this, participants felt that there should be a carefully designed process of informing people why they did not meet the eligibility criteria or why their choices of treatment or service were not included in the care plan. There needs to be clear information about how eligibility criteria are determined, how assessments are made and how decisions are taken.

2. The introduction of personal health budgets must not lead to valued existing services being closed

Strong views were expressed in all focus group discussions that a move over to personal health budgets, combined with recent cuts to local services, would result in service users and carers struggling to find the support they need. Some were even suspicious that personalisation was a way of introducing “cuts through the back door”.

“I don’t feel isolated in [the day centre] as I do in my local community... but because of the individual budgets I can no longer afford to go.”

Service user (survey)

Participants struggled to see how personal health budgets could be brought in while those services they did value were maintained, particularly at a time of financial constraint. They warned that if current providers became financially unviable because a minority of people spent their budgets elsewhere it could lead to those left having less choice overall.

Participants from BME communities felt that this was a particular risk for them. Some were observing their local authorities reducing the support given to culturally specific services and encouraging people on to personal budgets instead, yet there were no alternative providers from whom to buy these services.

3. Personal health budgets must be adaptable to fluctuating health needs

A key concern that emerged in discussions about choice was that personal health budgets would need to be flexible enough to work within the context of fluctuating needs created by many mental health conditions. Service users would be unlikely to want to take up a personal health budget if short, temporary changes in their health meant losing the

budget and having to start the process of assessment, care planning, eligibility and resource allocation all over again.

Similarly, participants felt they needed assurance that personal health budgets could adapt quickly to change, and would in no way preclude them from receiving more services if their health worsened suddenly.

“If you were given the personal budget, you’re using it properly, you’re using it absolutely fine for, say, six months or whatever and then something very traumatic happens and it triggers a manic episode, which won’t last forever but you have a blip, what happens then?”

Service user (FG4)

4. Personal health budgets must not widen health inequalities

There was some concern that the introduction of personal health budgets might increase inequalities in the mental health system. Some participants felt that unless a concerted attempt is made to support service users and carers in thinking through their options and choices and to help them voice their needs, only the more articulate and able people will have access to them, leaving others behind.

Knowing how to articulate their needs was a key issue for people from BME communities, many of whom faced additional barriers in communication and in negotiating structural and bureaucratic obstacles in mainstream services. They relied on advocacy and support workers from their communities to mediate across these barriers, but were now observing the closure of many of these services. An increased level of independence under personal health budgets would probably lead to an increased need for support.

“You know, a lot of people from BME communities are not heard, because we can’t communicate with confidence. When we’re not speaking from a place of confidence, professionals look down on us or they don’t give us the services.”

Carer (FG3)

Both of the BME focus groups and two others felt that it was important to recognise the existence of racial and ethnic inequalities in mental health service delivery. This included the over-representation of people from some BME communities in acute services and under treatment orders⁹ and their under-representation in referrals for talking therapies.¹⁰ There was a risk that the freedoms offered to those on personal health budgets could exacerbate these divides unless appropriate support and advocacy is given to those with poorer mental health, a degree of national uniformity in their delivery is ensured, and existing inequalities in the system are challenged more strongly.

5. Service users and carers must be given appropriate levels of support at every stage of the personal health budgets process

The most common request for support that participants felt they would need was a dedicated personal health budget adviser to act as a ‘one-stop-shop’ for information and guidance. These people should be located within mainstream services and in voluntary and community sector organisations. The idea that peer support models could fulfil some of these functions was widely supported.

The key roles and skills of these advisers should include:

- acting as an advocate and ally to service users and carers in conversations with professionals
- assisting in the application, budget management and care planning process where needed
- understanding the specific cultural and linguistic needs of service users and carers
- developing the necessary skills in budget holders to act independently
- managing rejection in the event of an application being denied.

6. Personal health budgets must be accompanied by a shift in organisational and professional culture towards partnership and supported risk taking

As outlined on page 13, there is scepticism over the extent to which personal health budgets on their own could overcome established ways of working in the mental health system. Their introduction would need to be accompanied by a concerted effort to change organisational and professional cultures so that managers and clinicians begin to trust service users and carers to take a much more equal and active role in their care. They would also need a change in risk-averse attitudes to delivery for the aspirations of personalisation and recovery to become reality.

7. Personal health budgets must be aligned with personal budgets in social care and grounded in a broader social understanding of mental health

Any system of personal health budgets must be used to challenge, not perpetuate, the divisions that exist between the health and social care systems. Integration should not just focus on processes – although it was important that personal health budgets did not duplicate bureaucracy – but also on the understanding of mental health shared across commissioners, providers and community groups.

NHS Confederation viewpoint

It is encouraging that the frustrations expressed by the service users and carers in this study match up to things personal health budgets are intended to improve – listening, control, integration and innovation. This shows that those working to develop personal health budgets have understood the problem correctly.

Yet very few of the people we spoke to thought personal health budgets would be an effective solution if mental health services did not radically change first. In contrast to many, they appear to see personal budgeting as something that has to follow from participatory healthcare, rather than something that allows them to demand it. This conflicts with some of the views we have encountered in our previous studies on this topic.

Service users and carers appear to share the scepticism of local leaders over the acceptability of personal health budgets to NHS staff, something which our last report on this issue confirmed. They feel that they have seen little change as a result of previous national policies to promote personalisation, and do not believe that personal health budgets are capable of compelling clinicians into changing their behaviours. Interactions between service user and health professional are private – participants did not see how national policy can influence this environment. This reinforces the conclusion from our last report that clinicians must be convinced, not coerced, into adopting personal health budgets into their practice if trust between them and their service users is to be rebuilt. We therefore repeat our recommendation that the Department of Health rethink the role it is currently giving to the national evaluation, extend its duration, and begin an extensive programme of professional engagement as soon as possible.

It is clear from the concerns and recommendations on pages 18 to 20 that a lot of work still needs to be done to make sure that personal health budgets are fit for purpose.

Particularly challenging will be the demands from service users and carers to:

- protect the viability of valued existing services
- ensure that inequalities in health do not increase
- integrate personal health budgets with their social care counterparts.

There remain many unanswered questions that prevent us from being able to reassure people over these concerns. The pilot sites will help towards some of the answers, but it is clear that a lot more work is still needed for this policy to be ready for roll out.

If these concerns can be addressed, it is clear from this study that a significant number of service users and carers, but by no means a majority, would consider taking up a personal health budget. This suggests that in thinking forward to the implementation of this policy we need to plan for a system in which personal health budget holders make up an important part of the NHS, but most eligible patients do not choose to take one up. This would not be a failure of the policy. In our view, even a small proportion of patients acting as customers of their health services could have a profound effect across the system.

Having now conducted studies into the views of senior managers, frontline clinicians and potential future recipients of personal health budgets, it is clear that there are many points of shared opinion and many tensions between these groups. We will shortly be publishing further analysis and reflections on what these reports mean when taken as a whole.

For more information on the issues raised in this report, please contact mentalhealthnetwork@nhsconfed.org

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Personal health budgets

Completing our series of studies into what key groups in the NHS think of personal health budgets, this report examines the views of mental health service users and carers. It outlines the frustration that people feel with the level of involvement that mental health services currently offer, but shows that their opinions of personal health budgets are mixed. There is scepticism

over how this national policy can effectively change the current culture of provision on the ground.

With the evaluation of personal health budgets pilots due to be published in October 2012, the report gives recommendations for how Government and local NHS organisations should proceed.

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