Personal health budgets in England – making them work in mental health

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About Mind

Mind is the leading mental health charity in England and Wales.

We provide advice and support to empower anyone experiencing a mental health problem. We campaign to improve services, raise awareness and promote understanding.

We work in partnership with over 150 independent local Minds to provide a range of services tailored to the needs of their local community. Services on offer include supported housing, crisis help lines, drop-in centres, counselling, befriending, advocacy, and employment and training schemes. Last year our network provided direct support to over 285,000 people.

Mind wants to ensure that people with mental health problems have their voices heard, and are treated fairly, positively and with respect.

Executive Summary

- The Government has committed to rolling out personal health budgets in the NHS in England for patients who could benefit from them. In line with the Government's commitment to 'parity of esteem' in the Health and Social Care Act, this should apply equally to mental health and physical health.
- The evaluation of the national pilot programme indicated that personal health budgets "had a significant positive impact on care-related quality of life, psychological wellbeing and subjective wellbeing"[1] of the people taking part. People with mental health problems reported improvements in their physical health, and people with physical health problems likewise reported better mental health. Personal health budgets were also shown to be cost-effective for people with mental health problems, reducing their use of primary and secondary care.
- Mind conducted research with people with mental health problems to find out what they want from services and support, and what role personal health budgets might play in improving their experience of care and their health and wellbeing outcomes.
- People with mental health problems told us choice of treatments and joint-care planning are most important to improving their experience of mental health care. These ideas are central to personal health budgets.
- Mind supports the principles behind personal health budgets of greater choice and control, a shared decision-making approach to care planning, and a focus on patient-defined outcomes and flexibility in how to achieve them.
- However, Mind has identified a number of barriers that threaten the effectiveness of the policy for people with mental health problems and has produced a series of recommendations to overcome them.
- We know that some people with mental health problems will not want a personal health budget, so it is crucial that enough existing services are provided to meet their needs.

1. *Evaluation of the personal health budget pilot programme*, November 2012

Summary of recommendations

Recommendations for Government

- Ensure parity of access for people with mental health problems as personal health budgets are rolled out, through a fair and holistic needs assessment.
- Introduce a right to request a personal health budget for people with long-term mental health problems.

Recommendations for NHS England

- Promote guidance on best practice in introducing and sustaining personal health budgets for people with mental health problems. This should include addressing the needs of people from BME communities.
- Ensure local systems are incentivised to enable parity of access and monitor their uptake among different groups.
- Collect information from Clinical Commissioning Groups and commissioning support units about their experiences of implementing personal health budgets and use this to inform commissioning guidance and to share best practice.

Recommendations for Clinical Commissioning Groups

- Commission good quality, accessible information that is available to everyone who might be eligible for a personal health budget
- Commission brokerage and support services to ensure people with mental health problems who want a personal health budget have the support they need to access and manage one
- Use information from how people choose to spend their personal health budget to inform commissioning decisions
- Put in place a transparent, flexible and timely process for applications for a personal health budgets
- Ensure that health and wellbeing outcomes and how to achieve them are self-determined

Recommendation for professional bodies, NHS providers and medical training institutions

- Provide professional guidance, training and support to help staff to develop the necessary skills and confidence to enable a culture change and shift towards greater shared decision-making and positive risk-taking

Recommendation for NICE

- Widen the evidence base to include more research into social and non-traditional interventions for mental health, including looking at qualitative research focussed on patient outcomes and experiences.

Recommendations for Health and Wellbeing Boards

- Assess and plan for the impact of personal health budgets on existing health services
- Explore how budgets in health and social care can be integrated at a local level
- Analyse and stimulate the provider market

Recommendation for mental health provider organisations, including those in the voluntary and independent sector, service user groups and other organisations who support people with mental health problems.

- Promote and disseminate information about personal health budgets to people with mental health problems, and signpost them to sources of information, advice and support to help them access a budget.

Background to our research

With the full evaluation of the pilot sites being published in autumn of 2012, Mind wanted to explore how personal health budgets could work in mental health. We were keen to hear what people with mental health problems want from services and support, and what role personal health budgets might play in improving both their experience of care and their health and wellbeing outcomes. In light of the high levels of dissatisfaction among people from some Black and minority ethnic (BME) groups with mental health services, and their disproportionate experiences of inpatient care, detention and compulsion, we were particularly interested to discuss their views on personal health budgets.

This research builds on Mind's *Putting Us First*[2] project, which aimed to ensure that more people with mental health problems could access personal budgets in social care. This work identified a number of barriers which meant that although people with mental health problems were among the groups most likely to benefit from access to a personal budget, they were least likely to be offered one. These barriers included:

- Lack of information among people using social care services and care co-ordinators about how to access and manage a budget.
- The difficulty of releasing funds from existing services to pay for personal budgets.
- A risk-averse culture among professionals, with personal budgets seen as more risky than traditional services, and doubts about whether people with mental health problems would be able to cope or make the best decisions.
- People worrying they would lose their group services if they took a budget.
- Lack of understanding of how to use a budget in a flexible way to support someone with a fluctuating condition.
- Fear that personal budgets would create extra work and bureaucracy for care co-ordinators.

Mind was concerned that the roll-out of personal health budgets in the NHS might face similar challenges. We want to make sure that lessons are learned from the experience in social care so that people with mental health problems who want a personal health budget do not miss out.

2. *Putting us First* was a Department of Health funded project focused on direct payments and individual budgets for people who use mental health services. It was a joint project between Mind and the Norah Fry Research Centre, University of Bristol that ran from October 2008 to March 2010.

Methodology

This report is based on research undertaken by Mind from June to October 2012, including:

- An online survey completed by 502 people who had used mental health services in the last two years.
- Two focus groups, one with service users of Dartford, Swanley and Gravesend Mind, and one with people from BME communities in East London.
- Interviews with people currently using personal health budgets for their mental health.
- Interviews with national and local stakeholders involved in the personal health budget pilots.

This provides a crucial early snapshot of the opportunities and challenges in rolling out personal health budgets to people with mental health problems. However, as the policy is still in the early stages of implementation, it has been challenging to identify many people with mental health problems who have a budget. Further research will be needed to understand their needs and to ensure they can equally benefit from the policy.

People's experience of mental health services

[I'd like] more control over my own care. I have had to go for private healthcare at a significant cost to my family due to lengthy waits and poor quality treatment. This is unlikely to be sustainable for much longer... but [I] was at rock bottom. I became tired of nobody listening to my opinions regarding my care, assessment and treatment and having no say on who provided any of this.

Respondent, Mind personal health budgets survey 2012

One in four people experience mental health problems in any given year[3] and mental health services play a crucial role in keeping people safe, providing support and helping them to recover. However, all too often people with mental health problems tell us that services can be difficult to access and variable in quality. With cuts being reported in some areas and widespread reorganisations at a time of rising demand, mental health services are under increasing pressure. We wanted to understand people's specific concerns about mental health services to see whether the problems personal health budgets set out to address were the right ones and whether they were likely to be able to provide a solution.

People using mental health services tend to report low levels of satisfaction with their treatment. While 43 per cent of people responding to our survey told us that they were satisfied or very satisfied with the services they use to support their mental health, a worrying 37 per cent of respondents told us they were dissatisfied or very dissatisfied. From our ongoing engagement with people with mental health problems, we know that they often have low expectations of mental health services and tell us they are grateful to have any services at all, however poor. This made the level of dissatisfaction even more concerning.

The key themes that emerged from our focus groups when we explored why people were dissatisfied were:

- Lack of information – GPs often lacked understanding of mental heath problems and treatments and didn't know where to signpost people for help.
- Long waits for psychological therapies – in some areas there were long waiting times to access psychological therapies, meaning the only treatment offered was antidepressants. Previous Mind research[4] has shown that 1 in 5 people waited more than a year to access psychological therapies.
- Lack of choice – there was a very limited range of services on offer for people to choose from.
- Lack of involvement – people told us that they didn't feel they had much say over their care, and that even when they were asked for their opinion, their views were often overruled by professionals.
- Not being listened to and treated with respect – many people told us they did not feel listened to and did not have their concerns taken seriously. They were often too frightened to complain if they weren't happy with their treatment, fearing there would be repercussions from staff, or that they would not be believed.
- Needs of people from BME communities – people from our East London focus group

3. The Health & Social Care Information Centre, 2009, Adult psychiatric morbidity in England, Results of a household survey

4. *We Need To Talk: getting the right therapy at the right time*, Mind 2010

reflected broadly similar concerns to other users of mental health services, and had mixed experiences of services being able to meet their cultural needs. They felt more could be done to make sure services can work across cultures.

So while some people are satisfied with the services they use and want to continue using them, there is also a significant group of people who were not happy and who might look to do things differently.

Benefits of personal health budgets

We wanted to look at whether personal health budgets could be a tool to address some of the shortcomings people identified in existing services. This section looks at some of the key features of personal health budgets and what people with mental health problems told us about them.

Greater choice and control

[I'd like] more choice and control over treatments. [It] would enable treatment suited to my needs and difficulties rather than me receiving treatment which is not appropriate to my needs.

Mind personal health budgets survey 2012

One of the key drivers behind personal health budgets is giving people greater choice and control over the support they access to manage their mental health. Mind supports this principle, as giving people more say over their own care can help to target treatment to meet their individual needs in a way that fits in with their own lives, increasing their prospects of recovery. For example, people who were offered a full choice of different types of psychological therapy were five times more likely to report that therapy helped them to return to work[5]. We also know from our ongoing engagement with people with mental health problems[6], and other national research in this area[7], that having greater choice and control has therapeutic benefits in itself, particularly for people who have become disempowered after many years in services, and can improve people's confidence and self-esteem.

5. *We Need To Talk: getting the right therapy at the right time*, Mind 2010

6. Mind conducts regular focus groups, surveys and interviews with people with mental health problems on a range of issues.

7. *Direct Payments, Independent Living and Mental Health – An Evaluation,* Spandler & Vick, HASCAS 2004

Choice and control are particularly important in mental health where high levels of compulsion are common and the power imbalance between patients and professionals is particularly pronounced.

Our research suggests that most people who use mental health services value being able to exercise choice in a number of ways. 77 per cent of respondents to our survey said being able to choose the type of treatment/services they could access was very important to them, while taking part in joint-planning of their care (72 per cent) and being able to choose which professional treated them (61 per cent) were also very important.

However, the reality is that choice is not widely available. Only 11 per cent of respondents were always able to choose the type of treatment or service they received, with 34 per cent of respondents never able to do so. While 20 per cent of people were always involved in the joint planning of their care, 30 per cent were never able to do so. Only six per cent of people could always choose which professional treated them, with 63 per cent were never able to choose.

Lack of choice may arise from limited types of services being commissioned or available locally, staff reluctance to give people control or simply supply not meeting demand. By putting funds in the hands of people using services, personal health budgets can enable them to access a range of support and activities within or outside of existing commissioned NHS services, including those provided by voluntary and independent sector organisations, as well as mainstream activities within their community.

Although our focus groups were initially sceptical that such extensive choice would ever be available through the NHS, as this had not been their previous experience of services, once we explained the idea in more detail, most people were positive and had ideas about what they might do differently.

Shared decision-making approach and a changing role for professionals

Well, [I want] a holistic assessment; look at me from the top to the bottom and to be honest about things – because, you know, it's about working in partnership... I think in mental health a lot has been just going along with the service user and not actually feeding back and asking, "what does this mean for you?... how would this help you?", to stimulate a person's thought process.

Mind focus group participant

Mind welcomes the opportunity for greater partnership working between patients and professionals through the planning process that lies at the heart of personal health budgets. All too often, people with mental health problems tell us that they feel important decisions about their care are made when they are out of the room. Many people told us they have limited input into their care plan and that they feel that care planning is a tick box exercise. Indeed, 45 per cent of respondents to our survey said that they were rarely involved or not involved at all when decisions were made about the care they needed. The recent Care Quality Commission report on Monitoring the Mental Health Act found that 63 per cent of inpatients now have their views recorded in the care plan, but this still means that more than a third did not have their views written down[8]. This lack of genuine involvement is particularly concerning as mental health is often seen as ahead of the game in terms of patient involvement, compared with other areas of health, and gives an indication of the scale of the challenge in making patient involvement a reality across the NHS.

Where people had a good relationship with their GP, psychiatrist or Community Psychiatric Nurse, they told us how important this was in keeping them well. Worryingly, a number of people spoke of considering themselves "lucky" if they were allocated someone who listened to them and understood what they needed.

Mind believes that personal health budgets offer an opportunity to move towards genuine shared decision-making in which:

- both the lived expertise of the person and the clinical skills of the professional are recognised, with decision-making powers shared more equally in an environment of mutual respect
- the conversations that take place as part of planning someone's care allow for a genuine dialogue between patient and professional, with space for each to constructively challenge the other
- the person's skills and assets as well as their needs and vulnerabilities are identified and
- solutions are sought that address not just someone's medical symptoms but rather that look to fit in with and enhance their whole life, such as employment or voluntary work, their family commitments and friends, their physical health and broader interests and values, including their faith or spirituality and their cultural heritage.

However, personal health budgets are only one tool for achieving this, and we want to see this approach rolled out more broadly across all mental health services, regardless of whether someone has a personal health budget or not.

8. *Monitoring the Mental Health Act in 2011/2*, Care Quality Commission 2013

A focus on health outcomes, not services

There are so many services which support people's health, which are not accessible to many people with mental health problems... these budgets could be used to allow them to access services, e.g. I tried to use the local referral for exercise services, and dietetic services, but my mental health problems prevented me from using them." Mind personal health budgets survey 2012

Mind personal health budgets survey 2012

[I would use a personal health budget] to cover the costs of exercise and maybe doing a part-time course to help me get back into social atmosphere and improve work prospects and help with being able to eat more healthily."

Mind personal health budgets survey 2012

Mind welcomes the focus on health outcomes within personal health budgets, allowing people to self-determine what kind of support, services or activities will best meet their health and wellbeing goals. This can enable people for whom traditional services have not been effective to try a different approach more tailored to them. It also gives people space to identify broader goals that go beyond managing the symptoms of their mental health problems, to identify what a good life looks like for them.

Personal health budgets enable people with mental health problems to access interventions which have been traditionally considered part of social care, as long as they meet health and wellbeing goals. Mind supports this, as we have long argued that for people with mental health problems, the distinction between health and social care is not very meaningful. We have seen that 'social' interventions provided by our local Minds, such as dancing classes, cooking clubs, art groups and alternative therapies are hugely beneficial in supporting people to manage their mental health, as well as helping to reduce social isolation and build resilience.

Respondents to Mind's survey were interested in a range of services or activities to meet their mental health needs. The most popular choice was accessing psychological therapies. Participants in our focus group were also supportive of this, particularly as in their local area, there were long waits for talking treatments. People also wanted to be able to access different types of psychological therapy, or longer-term therapy that was difficult to access on the NHS.

People were also interested in employing a carer or personal assistant to help them with household management, shopping and keeping on top of their finances. Help with the costs of travel and transport was also a popular option, as was joining a gym or purchasing home exercise equipment. Exercise on prescription schemes have become increasingly popular to tackle physical health problems, such as diabetes and obesity. However people with mental health problems told us they were often not able to access similar schemes for their mental health. Personal health budgets could be a way to drive parity of access to these types of approaches, which are recognised as beneficial to wellbeing, for people with mental health problems.[9] Given people with mental health problems experience worse physical health than the wider population,

9. *Ecotherapy – the green agenda for mental health*, Mind, 2007

there is a real opportunity to improve both physical and mental health through the same funding stream.

People from our BME focus group spoke of the importance of all services they might use being culturally sensitive and able to work across cultures. Some people wanted to be able to access services provided by people from their own community, while others preferred to use mainstream services but wanted a greater understanding of their cultural and spiritual needs within those services.

We know that in social care, people have used a personal budget to access services that meet their cultural and language needs, for example, personal assistants from their own community who share their language, or to have meals that match their usual diet. There was also an example from the personal health budgets national pilot of someone using their personal health budget to attend counselling with an Urdu-speaking counsellor.[10]

We know that people from some BME communities have had very negative experiences of mental health services and are often reluctant to engage with them. They often delay accessing support until they are in crisis and as a consequence are overrepresented as inpatients and more likely to experience detention and compulsion, and conversely are less likely to access primary care mental health services. Given the proper support to access and manage a budget, personal health budgets could be used to enable people from BME communities to access support for their mental health earlier and in a way that puts them in control and gives them the opportunity to identify what works best for them.

The nature of our survey and focus groups meant that we weren't able to take people through a realistic planning process to address their individual needs. However, where this had happened within the pilot programmes, we heard via our stakeholder interviews and broader research about some really innovative uses of budgets to help people, some of whom had been in services for a long time, to manage their mental health more effectively and also to move forward with their lives. These approaches enabled people to address multiple issues in their life through their package of support. Mind is very supportive of people being given the tools and support to identify their own needs and to define what recovery looks like for them, based on their whole lives and the wider determinants of mental health.

People with mental health problems are often experts in their own symptoms and support needs, but have never been given the opportunity to have control over their care. Mind supports the maximum flexibility possible in the use of budgets, enabling people with mental health problems to take control of their lives. We were pleased that the evaluation confirmed our view that budgets work best where they were used most flexibly.

The evaluation showed that non-traditional services can be effective in managing mental health. This chimes with what people with mental health problems often tell us about how they manage their condition. Mind would like to see further research to broaden the evidence base on the efficacy of social interventions and alternative support methods in mental health. Randomised controlled trials are not always the best way to assess this, so other forms of qualitative research, focussed on what people with mental health problems report about their experiences and outcomes, needs to be accepted as valid evidence.

10. Razia's personal health budget story, Department of Health

Case study - Alex

Following a stroke, Alex developed clinical depression and received treatment from the local community mental health team. He was approached by his occupational therapist to see if he would like to take up a personal health budget. Through the planning process, he identified his health and wellbeing goals as:

- improving his circle of friends, feeling comfortable with people and being able to ask for help
- being able to contribute to society in some way
- being organised and in control
- having more confidence in making decisions and choices
- regaining confidence in interacting with people
- being able to manage stress

He spent his budget on:

- a SatNav for his car as he found after the stroke that he got lost easily. This enabled him to attend his stroke survivor group and give lifts to other members, building his circle of friends.
- a tablet organiser to help him stay organised and also develop IT skills.
- employing a personal assistant, to help with opening mail and "keeping bad news away". She also checks that his diet is good and that he's taking his medication.
- Attending a weekend stroke survivor conference to meet other people in the same situation and to share what he learned with other members of his local group.
- Instead of having physiotherapy, he bought a set of drums and goes for a drumming lesson every week. This is something he enjoys, he's learning something and it has helped improve the coordination skills he'd lost as a result of his stroke.
- Having some counselling sessions for his depression.

He says it has definitely helped him to manage his mental health better. "Having a PA means my lifestyle is healthier, I have a better diet and feel better about myself. It gives me a little bit more enjoyment to get out and meet people, and become more confident with my peer group. My general health has improved dramatically and I sleep better at night. I also go to hospital less and less."

"It's a fantastic idea, giving people the opportunity to experiment with alternative treatments and giving people a better chance to find something to suit their individual needs. It's given me the chance to learn new skills and develop skills I have lost. Then I can help other people. It's given me a purpose because people are relying on me."

Examples of how personal health budgets were used in the Merseyside pilot programme[11]

- **Courses** – college courses were used by people to increase their social inclusion, to occupy their time, teach them new skills and to spend time doing something they enjoyed. Someone also took a two-day chainsaw certificate course to add to their skills and qualifications so that they could set up a business as a tree surgeon.
- **Laptops** – these were often used to support communication and staying in touch when someone couldn't go out because of their mental health. For example, a mother with small children couldn't get out to the shops easily, so she used the computer to order food deliveries. She was also able to increase her IT skills and help children with their homework. Another personal health budget holder used her laptop to keep in touch with her family in Pakistan, reducing her social isolation.
- **Holiday** – someone who'd had a long period of severe depression was coming to the end of their support from the community mental health team. She felt during her recovery that she wanted to be able to give something back to her husband for supporting her when she was unwell. She used the budget to pay for a holiday in the Lake District with her husband. This helped her draw a line under her illness and gave her a better sense of self-worth. A year later, she still thinks about the holiday most days and thinks of it as a watershed. She'd previously worked in administration and planning the holiday helped her regain confidence in her administrative skills. She is now a trustee for a charity.
- **Exercise** – people took out gym membership, attended martial arts classes, and went canoeing to improve their physical and mental wellbeing. For someone who struggled to get out because of their mental health, they bought WiiFit to build health and fitness with a view to feeling better about themselves and starting to go to the gym in the future
- **Clothing** – one person had put on a lot of weight after being in hospital and used the money to buy clothing store vouchers so that they could feel more comfortable about their appearance.
- **Vocational uses** – several people used their budget to set up small enterprises, for example to purchase card making equipment, ironing equipment, art materials and to put towards a van for a carpenter.

11. Personal Health Budget National Pilot Programme

Examples of health and wellbeing outcomes from the Northamptonshire pilot site[12]

Here are some examples taken from the Northamptonshire pilot site of what people spent their budget on and the health outcomes they identified, in their own words.

- Payment towards a vehicle and vehicle repair costs – to reduce isolation
- Mattress and pillow – to help me sleep
- Payment towards clothing – to feel comfortable and confident about my appearance, which increases my self-esteem and motivation
- Laptop – to support me to pass my college course
- Holiday with dog – to rest and recuperate
- College course – long term goal to be in employment and financially independent

12. Personal Health Budget National Pilot Programme

Barriers to making personal health budgets work in mental health

While the introduction of personal health budgets has the potential to benefit people with mental health problems, the right systems, support, information and staff training need to be in place if they are to have equal access to budgets. This section looks at some of the key barriers to implementation our research identified.

Widening health inequalities

The trouble is you spend your whole time fighting to get somewhere and then when somebody does offer you something like this it's quite scary. You're so used to being told what to have.

Mind focus group participant

It's no good just dumping us with all this money and saying 'bye. Especially for people that are just finding the courage to speak to somebody and they haven't had any prior help. They won't know where. So it's good to have a choice but then if you're not being made aware of what choices there are, that's obviously an issue. That would be really helpful. And if you had somebody to go through with you what's available it would really help people manage that.

Mind focus group participant

The experience in social care has been that the uptake of personal budgets among people with mental health problems (9 per cent of those eligible) was significantly lower than for people with physical health disabilities (35 per cent) and learning disabilities (41 per cent)[13].

Respondents to our survey told us they would struggle to access a budget without ongoing help and support. They feared that people who were the most articulate, had strong support from family and friends and perhaps were not so unwell would benefit from personal health budgets, while those who lacked confidence or did not have support would miss out. It is particularly important that this does not happen as the evidence suggests that people with mental health problems are one of the groups most likely to benefit from a budget.

People from BME communities face additional barriers in accessing services and support, and are less likely to access primary care mental health services, such as psychological therapies. This may be because they are not aware of what is available or because the services on offer are not appropriate to their cultural or linguistic needs. Mind believes that personal health budgets could be a powerful tool to address the existing ethnic inequalities in mental healthcare, enabling people from BME communities to access services and support before they reach crisis point and and empowering them to purchase support that meets their cultural needs. For people who have disengaged with existing services, personal health budgets offer them an opportunity to put in place alternative support to help them to recover.

The availability of good support planning and brokerage services will be particularly important in mental health if parity of access to budgets is to be a reality. These services need to be responsive to the needs of everyone with a mental health problem, but particularly to people from BME communities, given the additional cultural and linguistic barriers they often experience in accessing services. They should

13. Association of Directors of Adult Social Services, 2010–11

tap into existing expertise within the community and voluntary sector to make sure that personal health budgets do not widen health inequalities. Access to peer support and advocacy services can also help people to access and manage personal health budgets.

Low awareness and understanding of personal health budgets

I am extremely worried about their introduction...They are creating a great deal of worry and uncertainty, which obviously can compound the difficulties people are already experiencing.

Respondent, Mind personal health budgets survey

Our research suggests there is currently very limited awareness and understanding of personal health budgets among potential budget holders. Only 12 per cent of respondents to our survey said they had a good understanding of personal health budgets, while 47 per cent had never heard of them at all. In particular, we encountered a lot of confusion with personal budgets in social care.

In this context, people had many concerns and some misconceptions about what budgets were and how they would be affected by them. These included:

- Eligibility – people thought they wouldn't be considered unwell enough to receive a budget, that they'd be means-tested or that their benefits would be affected
- Assessment – people feared the use of a needs assessment which would not give them a fair chance as mental health is often a hidden condition, replicating the problems they are experiencing in the welfare system[14].
- Too burdensome – applying for and managing a budget would be stressful and time-consuming, particularly when someone was unwell, and they feared being left to manage alone.
- Bureaucracy – there were concerns that staff and systems would not be able to cope with administering budgets, leading to delays and unfair decisions.
- Exceeding their budget – people wondered what would happen if they spent all of their budget and needed further help – would they still be able to access services or would they be expected to make up any shortfall?
- Unnecessary – if existing services listened and offered more choice, there would be no need for personal health budgets.
- Funding – people who are seeing local services cut wondered where the money was coming from to pay for budgets.
- Lack of knowledge about treatment options – some people felt they weren't best placed to decide what would work best for them and might be too unwell to make decisions.
- A cover for cuts – people also expressed concerns that they would in effect be given the job of cutting their own services.
- Privatisation agenda – some people told us they were worried that personal health budgets were the first step to a US-style insurance-based health system, and that budgets would lead to privatisation of NHS services and the

14. Mind has longstanding concerns about the Work Capability Assessment. For more information, see our submission to Professor Harrington's Year 3 Independent Review.

gradual reduction in universal services free at the point of need.

- Questions about appropriate use of public money – people found it difficult to understand why NHS funds were being used to pay for items such as laptops while others were struggling to access basic care.

People told us that service reorganisations and some cuts to mental health services in their local area are already having an impact on them. As a result, there was understandable hostility to further potential upheaval, with low levels of trust about the motivations behind it. Tightening eligibility criteria for social care and a squeeze on disability benefits, plus a stigmatising media narrative focussed on 'scroungers' has left many people with mental health problems feeling unsupported and even under attack. So there is an urgent need to provide more information to people with mental health problems about what personal health budgets are and how they would work.

Threats to services for people who don't want a budget

It would be too much extra stress for me to be buying my own healthcare, wouldn't it be better if professionals just listened to me in the first place, arranged what treatments/services I would need and then provided them normally?... It just seems unnecessary to actually give me money that I then pay for services I've agreed on in a care plan, care plans should happen anyway and lead to a referral.

Respondent, Mind personal health budgets survey 2012

As part of our survey, we asked whether people would be interested in applying for a personal health budget. 31 per cent of respondents said that they were interested, with 15 per cent not interested. The remaining 54 per cent were not sure, generally because they didn't know enough about them to say either way.

A number of people were happy with existing services and didn't want to change anything. Some people said they felt too unwell to make decisions about their own care and didn't want the hassle of a budget. A small number of people cited very negative experiences of personal budgets in social care as a reason why they were very reluctant to try budgets again.

Choice must include the right to exercise a choice not to have one. However, people should be fully informed about the possibilities and flexibilities that personal health budgets could bring to them, with enough assistance to make an informed choice about their care, and support to help access this.

People who decide that a personal health budget isn't for them need to be able to continue to access the mental health services they currently rely on, or to be helped to think about suitable alternatives. As there will be no new money to fund personal health budgets, funding will have to come out of existing block contracts for mental health services. As this happens, there needs to be serious thought given to how this will impact on the people who use existing services and how viable services can be sustained.

There also need to be other ways to increase choice and adopt shared decision-making approaches for people who don't want a personal health budget, such as better joint-care planning and greater use of user-defined outcomes. Commissioners, providers, clinical professionals and people who use services will need to work together to co-produce and design services that make this a reality.

Paternalistic attitudes and risk-averse cultures in the NHS

Do staff listen? I don't think they listen. I think sometimes their attitude can even be patronising and they don't treat you as the expert in your condition. You know how the medication reacts with your body... it makes you not want to take the medication because the side effects can make you not able to function. And then they want to give you more tablets for that... [Then you] try to get it changed and say you don't like something, they take it as you... refusing treatment.

Focus group participant

While some of our focus group participants had very good relationships with the professionals who support them, many people told us that they often don't feel listened to and that their wishes and concerns were not taken seriously. This is compounded by inherent power imbalances created by the existence of the Mental Health Act and the threat of compulsion. Mental health services also tend to be risk averse, with professionals fearing that people with mental health problems can't be trusted or won't be capable of making choices about their care and support. We know that these attitudes are often based on good intentions but have the effect of being very disempowering for people with mental health problems.

We also heard as part of Mind's crisis care campaign[15] that individual professionals fear that they won't be supported if a decision they make leads to something going wrong. If people with mental health problems are to receive equal access to personal health budgets, in line with the Government's commitment to parity of esteem, there will need to be a significant shift in attitudes and ways of working to enable positive risk-taking. There also needs to be recognition that existing services are not without risk, amongst which are actual harm that takes place in mental health settings as well as the risk of people not getting the help they need to recover.

Medical staff are currently trained to take responsibility for and make decisions about patients' care. With increasing demand for a more responsive, patient-centred NHS, staff will need to be supported and trained to develop the skills necessary to deliver shared decision-making approaches across all services, not just in the delivery of personal health budgets. This should include an understanding of the principles behind shared decision-making, and practical tools, such as motivational, coaching or non-directive interviewing techniques and using Wellbeing Recovery Action Plans (WRAPs) or equivalent tools. For new staff entering the medical professions, this training should form part of the core curriculum.

In addition, Mind recommends mandatory mental health awareness training, which involves people with mental health problems in its design and delivery, for all frontline staff in the NHS to help combat stigma and discrimination against people with mental health problems and to demystify common myths about mental health.

15. *Listening to Experience: an independent inquiry into acute and crisis mental healthcare*, Mind, 2011

Confusing, unfair or non-transparent processes

I and my cousin have experienced hell in getting his personal budget [in social care]... They have not listened or taken onboard his views and wishes or his cultural preferences... Personalised budgets and their administrative structures are meant to be flexible to meet needs, move away from basic services and to be adaptable to the individual. In this case, all has failed.

Mind personal health budget survey 2012

People's hopes and expectations will be raised when they are given the possibility of having more control over their care and support. Many of the negative stories we heard from social care were about the practicalities of the process. People told us about:

- long delays in getting a decision or in the budget being paid
- lack of a clear sign off procedure, or too many decisions being referred to a panel, leading to delays
- not knowing the amount of the budget prior to beginning the care planning process
- not knowing how the amount of the budget was calculated
- lack of clarity about how budgets were being approved and disappointment when people were turned down for something they requested without a proper explanation.

A number of similar experiences have emerged from the evaluation of the personal health budget pilots, which risk undermining confidence in the policy if they are not addressed as personal health budgets are rolled out. We know that in social care and in some of the personal health budget pilot sites, voluntary sector brokerage and advice services have been used successfully to help with both support planning and the administration of budgets. They can play a crucial role in supporting people to navigate the process and helping them to make informed choices. Including peer support from people who have used a personal health budget themselves as part of brokerage and advice services can help to ensure these services reflect the needs and experiences of people with mental health problems.

The fluctuating nature of mental health problems means that people's needs are likely to change over time. Personal health budgets need to be able to respond to this, so that if someone's condition deteriorates, they can be rapidly reviewed and given greater support if necessary. The use of advance planning tools, such as joint-care planning, crisis planning, and advance directives, setting out what someone would like to happen when they are unwell, can help to ensure that periods of crisis are factored in and anticipated and that contingency plans are in place. These should also cover what would happen if someone became too unwell to manage their budget.

It is essential, when reviewing a person's needs, that the impact of the services and support the person is currently receiving are taken into consideration. We have heard of numerous cases in social care where care and support services helpfully reduce an individual's visible needs but are then withdrawn, without consideration of the preventative nature of this support. This results in a significant deterioration in the person's mental health, and the requirement for more intensive and expensive support to help them to recover again. It will be crucial to ensure that the same mistakes are not repeated as personal health budgets are rolled out.

Example of using a voluntary sector brokerage service in the Merseyside pilot[17]

The contract for brokerage, and subsequently project management, for the Merseyside personal health budget pilot was won by Imagine Mental Health, a voluntary sector organisation with experience in social inclusion and day service modernisation through personalisation. They had also been working in partnership with Mersey Care NHS Trust on individual recovery budgets, including through Early Intervention in Psychosis. In total, around 200 people with mental health problems were given one-off budgets of between £400 and £1,000 to spend on something they thought would help them with their mental health. This has enabled people to achieve goals that are directly linked to improving their mental health.

The Imagine Mental Health broker was embedded within three community mental health teams and interviewed all individuals who applied for a budget face-to-face to discuss how they wanted to spend their budget. Imagine Mental Health held the funding that was made available for budgets, with the broker able to make purchases on behalf of budget holders via a company credit card. This meant they were able to provide a more responsive and reactive service than is sometimes possible within the NHS while remaining collaborative with the care manager.

There was also a clear process for sign-off to enable timely decisions. Three signatures were needed for a plan to be approved – those of the broker, the individual and the care coordinator. Budgets of up to £400 could be approved by the care-coordinator, as long as they were comfortable doing so. If they weren't sure, decisions would be escalated to the team manager, then the multidisciplinary team meeting and finally to a risk enablement panel, which included people who used services. In practice, people did choose to spend their budget in ways that were appropriate and in fact the panel did not need to be convened.

17. Personal Health Budget National Pilot Programme

Making personal health budgets work in mental health

Based on what people with mental health problems have told us, Mind is supportive of the principles behind personal health budgets. However, there is a real risk that without the right support in place, people with mental health problems will struggle to access them on equal terms to people with long-term physical health problems. Below are our recommendations of what needs to be in place if those people with mental health problems who want a personal health budget are to be able to get one, and if services for those who don't want one are to be sustained.

Recommendations for Government

- Ensure parity of access for people with mental health problems as personal health budgets are rolled out, through a fair and holistic needs assessment.

As part of the Government's commitment to parity of esteem for physical and mental health, the needs assessment used to determine eligibility for personal health budgets must take a holistic approach to health, including hidden symptoms and fluctuating conditions, taking full account of mental health problems from the outset and looking at people's whole lives and the wider determinants of mental health. It will be crucial to learn from the experiences in welfare assessments, and to have a test that people have faith in.

- Introduce a right to request a personal health budget for people with long-term mental health problems

To drive forward parity of access to personal health budgets, people with long-term mental health problems, including those with fluctuating conditions, should be given a right to request a personal health budget, mirroring the right NHS Continuing Healthcare patients will have from April 2014.

Recommendations for NHS England

- Promote guidance on best practice in introducing and sustaining personal health budgets for people with mental health problems. This should include addressing the needs of people from minority ethnic (BME) communities.
- Ensure local systems are incentivised to enable parity of access and monitor their uptake among different groups
- Collect information from Clinical Commissioning Groups and commissioning support units about their experiences of implementing personal health budgets and use this to inform commissioning guidance and to share best practice.

NHS England has a key role to play in making sure that people with mental health problems are able to access personal health budgets if they want to, in line with Objective 2 of the NHS Mandate. This specifies that by 2015 "patients who could benefit will have the option to hold their own personal health budget, subject to the evaluation of the pilot programme, as a way to have even more control over their care". NHS England should promote best practice guidance to CCGs on introducing personal health budgets for people with mental health problems and ensure that systems and support services are in place locally to enable them to access personal health budgets. This guidance should specifically address the needs of people with mental health problems and those of people from BME communities. As a first step, the guidance and toolkit prepared by the Department of Health should be disseminated and promoted to CCGs. As the policy is rolled out more widely, these tools should be reviewed and updated as necessary.

In social care, people with mental health problems have faced a range of barriers which have prevented them from accessing personal budgets. As a result, their uptake of personal budgets has been much lower than among people with learning disabilities and physical disabilities. CCGs and Commissioning Support Units should have to account for any lagging behind in roll-out

to people with mental health problems. They should also have to demonstrate what support they have in place to overcome the barriers people with mental health problems might face to accessing personal health budgets.

NHS England will need to have a good understanding of how successfully personal health budgets are being implemented at a local level, therefore CCGs and CSUs should be reporting on their progress with rolling out personal health budgets, both sharing information about good practice and highlighting the challenges they are facing in implementing the policy. NHS England should then use this information to continually update and improve the guidance and support they offer to CCGs, and to inform their broader commissioning support tools.

Recommendations for Clinical Commissioning Groups

- **Commission good quality, accessible information that is available to everyone who might be eligible for a personal health budget**

This should include information about what personal health budgets are, who can access them, the process for applying and how decisions are made. This should be made available from a range of sources including online, in GP surgeries, from Community Mental Health Teams and in local services, and in Citizens Advice Bureaux, libraries and other community hubs, including those used by people from BME communities.

To avoid exacerbating existing health inequalities, it will be important to ensure that the most marginalised groups are aware of personal health budgets and know who to approach to ask for them. These groups include people with mental health problems and people from BME groups and others.

- **Commission brokerage and support services to ensure people with mental health problems who want a personal health budget have the support they need to access and manage one**

Good quality support will be crucial if people with mental health problems are to be able to have parity of access to budgets. Brokerage and support services need to be able to meet the needs of people from BME communities to ensure they can access personal health budgets if they want to. People may not want to take on the full responsibility of managing a budget immediately, particularly if they have been in services for a long time and have become used to having decisions made for them. However, they should be empowered to scale up their level of decision making as and when they feel able to.

A range of organisations already have expertise in providing support, brokerage and advocacy services in social care, including some local Minds. The use of peer support should be extended to enable people to take more control over their care and their lives.

- **Use information from how people choose to spend their personal health budget to inform commissioning decisions**

The outcomes people with personal health budgets identify and how they choose to spend their personal health budgets offer a wealth of information about what people want from the support they access and what services they want to use. CCGs should capture this information and use it, alongside the feedback from ongoing patient involvement, to inform their decisions about what services or support to commission.

- **Put in place a transparent, flexible and timely process for applications for a personal health budgets**

There needs to be a transparent, fair and timely process in place so that people have a clear idea of what they can expect. This should include:

- Who is likely to be eligible for a budget and who makes the decision on who can apply

- How the budget is calculated
- What support is available to help people through the process of application and once they have a budget
- The basis for any decision
- Who can sign off the budget
- A clear explanation of why a request has been turned down
- Any appeals process, and what support people can get to help them appeal

Advance planning for crises should be an integral part of the planning process and the system has to be flexible enough to respond to fluctuating needs, so that if someone's needs increase, they are able to scale up their level of support accordingly.

- Ensure that health and wellbeing outcomes and how to achieve them are self-determined

People with mental health problems should be supported to produce their own health and wellbeing outcomes and to plan how to achieve them. CCGs should make sure that people with mental health problems are able to access services and support that meet their needs, rather than a specific type of service.

Recommendation for professional bodies, NHS providers and medical training institutions

- Provide professional guidance, training and support to help staff to develop the necessary skills and confidence to enable a culture change and shift towards greater shared decision-making and positive risk-taking

Buy-in from health professionals and a shift to a more equal relationship between patients are professionals are key to the success or otherwise of personal health budgets. Staff need to be supported through professional training and development so that they have the skills they need to work in partnership with patients to identify health and wellbeing goals. Staff also need to be supported to adopt a positive risk-taking approach to patient choice, especially in relation to mental health. This should include mental health awareness training, incorporating 'mythbusting' addressing the common misperceptions about mental health, and should challenge ethnic stereotypes around mental health.

Recommendation for NICE

- Widen the evidence base to include more research into social and non-traditional interventions for mental health, including looking at qualitative research focussed on patient outcomes and experiences.

The pilots and our evidence shows that non-clinical services can be hugely beneficial in improving people's mental health. However, we also know health professionals are reluctant for NHS funding to be released for "non-evidenced" interventions. NICE should therefore extend the evidence beyond randomised control trials, which are not always best suited to evaluating social interventions, to include qualitative research focussed on patient outcomes and experience[17]. More research is also needed to identify what people from different BME communities require to support their mental health.

Recommendations for Health and Wellbeing Boards

- Assess and plan for the impact of personal health budgets on existing health services

In advance of the wider roll-out of personal health budgets from 2014, there needs to be much more planning to understand the impact

17. See Social Care Institute for Excellence resources on mental health and personalisation

of budgets on existing services that many people rely on, including the implications of potential double-running costs, whereby CCGs are funding both existing services via block contracts and personal health budgets. Some people will never want a personal health budget so it is crucial existing services are sustained. Health and Wellbeing Boards are well placed to analyse this and develop plans across different services, as part of the Joint Strategic Needs Assessment leading to the Joint Health and Wellbeing Strategy.

- Explore how budgets in health and social care can be integrated at a local level

Health and Wellbeing Boards should explore how personal health budgets and personal budgets in social care can be better integrated at a local level, in recognition that the divide between the two is not very meaningful to people with mental health problems. This would also reduce the number of assessments people have to go through, offer the opportunity to give people a holistic package and is an opportunity to save money.

- Analyse and stimulate the provider market

Through the Joint Strategic Needs Assessment process, Health and Wellbeing Boards can understand mental health need and identify any gaps in the existing provider market. This can inform commissioning across the NHS and other services to ensure a wider range of services and support are commissioned to meet people's needs.

Recommendation for mental health provider organisations, including those in the voluntary and independent sector, service user groups and other organisations who support people with mental health problems.

- Promote and disseminate information about personal health budgets to people with mental health problems, and to be able to signpost them to sources of information, advice and support to help them access a budget.

Given the extremely low awareness of personal health budgets among people with mental health problems, service provider organisations have a critical role to play in ensuring people have the opportunity to find out more about personal health budgets and be supported to apply. Providers should make sure their staff know about personal health budgets, proactively talk to people about what they are and can signpost them to sources of further information, advice and support.

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