



National Mental Health
Development Unit

Mental Health Network

part of
THE NHS CONFEDERATION 

Shaping personal health budgets

A view from the top



Produced in association with

Directors of
adass
adult social services

The voice of NHS leadership

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- influencing policy, implementation and the public debate
- supporting leaders through networking, sharing information and learning
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- ensuring we are member driven
- putting patients and the public first
- providing independent challenge
- creating dialogue and consensus.

This report has been developed in conjunction with the Mental Health Network. For further details of the Mental Health Network, please visit www.nhsconfed.org/mental-health or contact Steve Shrubbs on 020 7074 3217 or at steve.shrubbs@nhsconfed.org

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The National Mental Health Development Unit

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

The NMH DU commissions or provides:

- 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 is 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.

Further information about the work of the NMH DU is available at www.nmhdu.org.uk

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Executive summary

Personalisation is a key aspect of future health policy, but how close is it to becoming a reality?

This report examines the views of 40 senior leaders from local health and social care organisations on an important lever in the personalisation agenda – personal health budgets. Our research, which took a particular interest in mental health, reveals that there is widespread support for personal health budgets as a concept and a strong consensus that they would offer significant benefits to many people managing long-term conditions. Most leaders are cautious, however, over whether implementing this concept is realistic or not.

While the outcomes from national pilots and some of their own local trials are awaited with interest, there is a desire to see the risks around personal health budgets taken much more seriously in the current debate. Most health leaders see the issue as too nascent to be a high priority and most are uneasy with the fervour of some proponents, who can make claims beyond that which there is evidence to support.

Three areas of concern were consistently raised:

- the cost and complexity of implementing and sustaining a significant number of patients on personal health budgets could be prohibitive
- the organisational culture of the NHS and the attitudes of its staff could resist devolving choice and control to users
- patients' safety and the quality assurance of the services they receive could be compromised as a result.

These concerns correlated with the challenges that the social care leaders we spoke to said they were facing already. Asked what the NHS could learn from these experiences, five main lessons emerged:

- creating the supporting culture is a far bigger challenge than developing the mechanism
- collecting stories of how personal budgets have impacted people's lives is an important tool in building momentum
- voluntary organisations are as vital as providers, trainers and advocates
- a coordinated local approach to personalisation, with agreement both across and beyond health and social care, is important
- the risks of such a new system can never be completely eliminated; at some point local leaders will have to display courage.

On page 20, we give our views on what the findings of this research mean. We argue that as personal health budgets move from theory into practice the tone in which they are presented must change. Employed in isolation from other aspects of personalisation, personal health budgets are likely to have minimal effect on the health system. Yet if a more balanced discussion around the risks and limitations of this new model of care is stimulated, and if evidence can be produced to support proponents' claims, leaders are far more likely to engage in the scale of transformation they know will be required.

Introduction

This report examines the opinions of 40 local health and social care leaders on the future of personal health budgets. It presents their understanding of the key issues, as well as their expectations, hopes and doubts. Our research took a particular interest in mental health services, but the findings are relevant across the NHS.

With the Department of Health now initiating a national pilot programme, personal health budgets are at a critical stage in their development as they

move from theory into practice. How local leaders shape and interpret this transition will be decisive to the success or failure of this new and innovative model of care. It is our intention that by setting out these views at an early stage, future debate can be as effective as possible. To support those leaders already planning to develop personal health budgets, this report also outlines the key lessons that have been learned from the experience of social care to date, in order to share good practice and help the NHS to avoid repeating mistakes.

What is a personal health budget?

According to the Department of Health:

“A personal health budget makes it clear to someone getting support from the NHS and the people who support them how much money is available for their care and lets them agree the best way to spend it.

“We do not think this will save money. We want to help people get a better service from the NHS without it costing more. The budget itself might not be that important – but we hope it helps people take a full part in discussions about their care. Most importantly, we hope that this effect – more open and honest discussions about what people want to change about their health and wellbeing – reaches people who do not have personal health budgets as well as people who do.”¹

The Department of Health identifies three ways in which a personal health budget could operate:

1. **Notional budget.** No money changes hands. The person finds out how much money is available and talks to their doctor or care manager about the different ways to spend that money on meeting their needs.
2. **Real budget held by a third party.** A different organisation or trust holds the money for the person, helps them decide what they need and then together they buy the services they have chosen.
3. **Direct payment.** The person receives the cash to buy the services they and their doctor or care manager decide they need. They have to show what they spend it on, but they buy and manage the services.

For more information on the technical background to personal health budgets, see the NHS Confederation's report, *Personal health budgets: the shape of things to come?*²

Methodology

This report presents the findings from semi-structured interviews with 40 local health and social care leaders across England. The interviewees represented:

- 15 primary care trusts (PCTs)*
- 16 mental health providers
- nine social services departments, nearly all of whom had uptake rates for personal budgets that were higher than the national average.

Most interviewees from the provider and commissioner groups were chief executives, with some at director level and a small number of personalisation leads. The majority of social services interviewees were directors of adult social care.

Interviewees were selected through email invitations and notices sent out to all chief executives of mental health providers, all chief executives and directors of commissioning (or equivalent) of PCTs, and all directors of adult social services, throughout England.

To ensure as representative a sample as possible, interviewees were selected from organisations spanning a range of sizes, population densities and locations. The PCT group was selected to contain eight organisations that had applied to participate in the Department of Health's pilot scheme and seven that had not. The provider group, while

primarily composed of NHS trusts, also included one for-profit and two third sector providers.

Interviewees were asked questions around six key themes:

- their experiences of personal budgets to date
- the priority level currently given to their development locally
- their expectations of how personal health budgets would progress nationally in the coming years
- the main effects that introducing personal health budgets would have on the NHS
- the main barriers to adoption and implementation of personal health budgets
- how these barriers could be overcome.

Additionally, social care interviewees were asked more detailed questions on their experiences of developing personal budgets to date, and were also asked to talk about the key lessons that the health service should take from these.

Interviews were recorded, transcribed by theme, then analysed for prevailing motifs as well as significant outliers. Aggregated findings were then sent back to the interviewees for further response or feedback.

* including two care trusts

Background

Personal budgets were first developed in social care as service users demanded greater choice and control over their care. Now a rapidly growing means of delivering personalised services, the NHS is to begin piloting their use.

The option to make direct payments to social care users has been available to local authorities in England since 1996. However, take up by most areas was low. In 2006/07 a national pilot was run with 13 local authorities to test individual budgets on a range of social needs. Evaluated by IBSEN, this pilot found that significantly improved user experiences and outcomes were rapidly achieved for most groups, and at an equivalent cost. Now labelled 'personal budgets', this model of care is fast becoming a mainstream option within a broader context of personalised social services, which includes person-centred planning and support for self-care. A new national indicator (NI 130) has now been created to encourage local authorities to achieve 30 per cent of their social service users holding a personal budget by March 2011.

The possibility of offering personal budgets to NHS patients was initially ruled out. The Government white paper *Our health, our care, our say* stated that extending such options into health "would compromise the founding principle of the NHS that care should be free at the point of need."³ With the release of the IBSEN evaluation and the debate which followed, however, this position changed. In the NHS Next Stage Review it was announced that

"in response to the enthusiasm we have heard from local clinicians, we will explore the potential of personal budgets, to give individual patients greater control over the services they receive."⁴ This document forwarded continuing care, long-term conditions and mental health services as viable options for trials.

With the Health Bill 2009 – as of November 2009 close to Parliamentary approval – set to enable NHS organisations to use direct payments, the Department of Health is in the process of building the infrastructure required to support personal health budgets. In May 2009, the Department of Health announced a list of 75 PCTs that had been awarded provisional status for a national pilot scheme. In October 2009, 20 of these areas were awarded full pilot status for in-depth evaluation. Those in the wider cohort who were not selected will still have the option to participate in the trial, but will be monitored in less depth.

As the national evaluation is set in motion, elements of personal health budgets are already being piloted through the Staying in Control community.⁵ This network of 37 English PCTs and their local authority partners seeks to share lessons and good practice around a broader range of issues relating to self-directed healthcare. The network's most recent discussion paper presents this as "achieving better outcomes by deliberately seeking to move power and control closer to the person, who is seen as an active citizen with rights and responsibilities."⁶

Are personal budgets right for the NHS?

Our research shows that the overall vision of personal budgets has almost unanimous support from NHS leaders, who point to their potential to substantially improve the lives of some patients. However, strong reservations around their practicality and risks meant that most leaders interviewed are conservative regarding the way forward. Leaders are keen to see whether the evidence for personal budgets can support proponents' claims. With the ideological battle now won, national pilots are the right approach.

What benefits could personal budgets offer the NHS?

The social care leaders we spoke to, most of whom were early adopters of personal budgets with high levels of uptake, unanimously reported better outcomes for their users as a direct result. While many noted that these gains are often hard to measure – for example, increased dignity and empowerment – quantifiable gains quoted included reduced admissions for mental health, fewer formal complaints and achievement of rapid success in those with the most complex needs.

Amongst the health leaders there was broad agreement about the kinds of benefits that they expect to be generated by introducing personal health budgets.

Firstly, the sense of empowerment would, of itself, improve the health and wellbeing of many patients, especially for those whom dependency on traditional services is hindering recovery. This was felt to hold particular potential in mental health.

Second, the ability for patients to design their own care packages would result in much more flexible

services, better able to fit around an individual's lifestyle. It could also lead to more creative use of resources, delivering more for less.

Third, personal health budgets could motivate the NHS to produce more effective patient information systems and resources.

Fourth, they would require health leaders to be more transparent over the cost of treatments. Several social care interviewees noted that this had been an unexpected benefit of personal budgets – it 'disciplined' their departments by having to publicly reconsider services which were costly yet unpopular.

Compromising the founding principles?

Although as recently as 2006 the white paper *Our health, our care, our say* dismissed using personal budgets in health as "compromising the founding principles of the NHS that care should be free at the point of use",⁷ just three of the 40 leaders we spoke to maintained this position. Of these, all objected on the grounds of the indirect effects on the health service; one because of the increased use of 'top-ups' that might follow their introduction; one because of the potential use of means testing to set eligibility thresholds; and one because the NHS could not refuse to treat someone if they misappropriated their funds, as social care could.

Having seen the local and national impacts of personal budgets emerging in social care, the vast majority of leaders we spoke to felt that there is no ideological reason why they should not also be the direction of travel in the NHS.

Fifth, the health leaders felt that by being forced to scrutinise their services from the patient's perspective, personal health budgets would stimulate improved cooperation and integration between local NHS organisations, local authorities and the voluntary sector.

Where personal health budgets could work best

It is clear that many areas of the NHS will never be appropriate for personal budgets. Little value is likely to be had from introducing them into A&E or specialist surgery, for example. Similarly, those providers running secure facilities for people with acute mental illness were clear that such services would be off-limits.

When asked which areas of the NHS they thought would be the most conducive to personal health budgets, the vast majority of interviewees indicated some form of long-term condition management or continuing care service. Popular suggestions included learning disabilities, dementia, end-of-life care and physical disabilities. Amongst the mental health providers, community-based and residential services were the most common suggestions.

Through further discussion with interviewees, a series of key factors emerged which, if present, would indicate that a service area would be more easily adaptable to personal health budgets:

- a clearly defined pathway of care
- easily quantifiable units of activity
- patients with stable, predictable needs
- regular contact with a health professional
- non-specialist interventions.

These factors show that leaders are looking to areas of the NHS where:

- it will be clear what the personal budget will and will not cover
- the cost of the existing service is simple to calculate
- the transaction costs of arranging a personal budget are spread over a long period
- improvement or deterioration in a budget holder's condition would still be detected
- the risks associated with giving patients more responsibility are low
- providers outside the NHS will be able to offer effective competing services.

The social care leaders we interviewed were unanimous that some use of personal budgets by the NHS, even if very limited, was necessary. Failure to develop any complimentary systems to those increasingly in use by local authorities risks creating new artificial boundaries for those people receiving health and social care services. This could result in many local areas having to retreat from progress made in recent years to develop a more integrated user interface. Despite this call, there was an acceptance that the NHS holds some different values to social care, and that health leaders would not be able to directly translate their local authority's model of personal budgets into their own.

Honest about the risks

As personal budgets move from concept to reality, the debate around them needs to change. Persuading the majority of health leaders to introduce them with any conviction will require a

more sober assessment of the possible consequences, intended and unintended.

Numerous interviewees – both providers and commissioners – expressed concerns that the current presentation of the personal budgets agenda was failing to take seriously enough the potential risks of the model. There was considerable frustration from many, even those actively seeking to run pilots, at the “evangelicalism” of some proponents of personal budgets. It was felt that enthusiasts are often over-confident in their claims beyond that which there is evidence to support, and several leaders shared personal experiences of feeling sidelined in public discussions when they had voiced anxieties.

“The traditional view of a pilot is that you do something and see if it works. In the NHS we do a pilot and it has to work.”

PCT chief executive

A related fear also expressed by health leaders, albeit a minority, was that the pilots of personal health budgets, currently in development, were a foregone conclusion. This group was mistrustful of the Department of Health’s record in translating the results of previous trials into new models of health provision. They wanted assurance that if improvements to outcomes were poor or negligible this would be acknowledged.

Case study: NHS Barnsley

NHS Barnsley is one of a small number of PCTs who are already offering some personal budgets through existing health service flexibilities. By delivering its adult mental health, learning disability, older people’s and physical disability services via a pooled budget hosted by its local authority, it is able to contribute small amounts of NHS funding to the locality’s personal budgets scheme. As of September 2009, around 700 people were receiving personal budgets for health or social care needs via the pool, with this number likely to double by March 2010.

The overall experience for patients with long-term conditions has improved significantly as a result of receiving more tailored care, examples of which include innovative respite solutions and contingency planning for those with fluctuating need. Other benefits which the trust has measured include reduced hospital admissions for some conditions and a lower incidence of crises amongst mental health service users.

However, the PCT’s chief executive, Ailsa Claire, is keen to stress that these early successes have only been possible as a result of the trust’s wider strategy of giving patients more choice. Personal budgets have to be seen as just one strand of a much wider self-directed care programme, she says, or they risk being “just another bureaucratic exercise.”

For Barnsley, this means coordinating personal budgets with plans for care navigation, self-assessment, social prescribing, telecare and improved information and advice. The trust’s strategic plan for 2008/09 states that its aim is to create “a shift in the relationship between the PCT and its local population from one characterised by paternalism to one of partnership and collaboration.”

How high a priority are personal health budgets?

Most of the organisations we spoke to were undecided about how extensively personal budgets will impact the NHS. Early evidence from national pilots and their own local experimentation is awaited with eager interest. However, unless personal health budgets can be proven to help solve current issues in the NHS, especially the financial crisis, they are unlikely to move beyond a niche model of care.

Little urgency

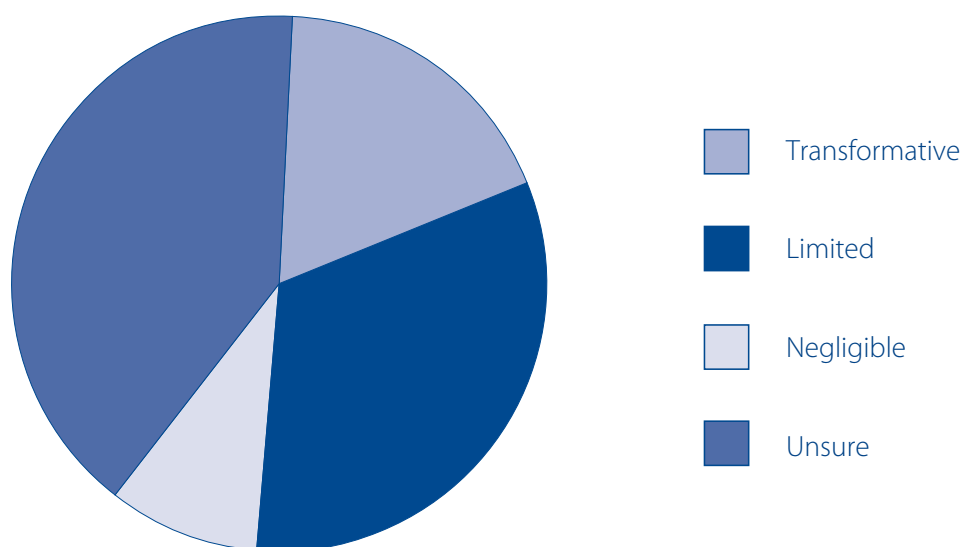
The health leaders we spoke to gave a wide and nuanced spectrum of views on how high a priority their organisations are giving to developing personal budgets over the next few years. While opinion ranged from indifference to intentions to transform whole service areas around them, the consensus was that personal health budgets

are an important mechanism to monitor and, in some cases, experiment with, but that anything other than a gradual evolution of the model is currently inconceivable.

Interviewees' predictions of the national development of personal budgets in the NHS reflect their local priorities. The most common response was uncertainty, with the results of national evaluations seen as the crucial determinant of the scale of future implementation. Almost as popular was the view that personal budgets are unlikely to filter down from national policy into local implementation. A significant minority anticipated major transformation, and only a few were already decided that personal health budgets have little or no future.

Early evidence on personal health budgets will be read by the leaders for two key factors, which

Figure 1. What impact do health leaders think personal health budgets will make on the NHS?



Source: NHS Confederation interviews

will determine how widespread they will become. Firstly, how challenging will the risks outlined in the following three chapters be found to be? Second, will the solutions that personal budgets are found to offer the health service be of a sufficient scale to justify a considerable period of service redesign and additional management resources, particularly during a time of shrinking funds?

Small share, big impact?

While one of the most common expectations of the health leaders we spoke to is that personal health budgets are unlikely to grow beyond a niche model of care, many of them see the potential for significant indirect impact on the health system. Several leaders, including some for whom personal budgets are a high priority, noted that even a marginal share of the health market, in terms of numbers of patients, could still have a dramatic effect on quality of care. As few as 5 per cent, or even 0.5 per cent, of patients on personal budgets, it was suggested, would provide enough of a threat to current providers to catalyse them towards developing services of sufficient flexibility and appeal that users would choose to remain with them rather than manage their own care. The degree of choice that personal health budgets could open up would create a market in which there were far fewer barriers to entry for many lower skilled health interventions, increasing the threat of competition even if only a small number of users actually chose alternative provision.

Moreover, a significant number of interviewees, particularly those in the high priority group, noted that many of the service reforms that would be brought about by introducing personal health budgets are being developed through their strategic plans anyway. They held that if the culture of an organisation is geared towards listening and

responding to the needs of their patients – the ‘softer’ aspects of personalisation – the mechanism of personal health budgets is not always essential, although it might accelerate the process.

Voluntary and private providers

Both of the third sector providers we interviewed were actively pursuing pilot PCTs to collaborate with and felt that although personal budgets brought significant risk to the voluntary sector, the ethos of their organisations meant that they were well matched to advocate and implement them. Similarly, both the for-profit provider and other NHS leaders pointed out the suitability of the private sector for personal health budgets. This was put down to their customer-focused attitude, experience of marketing themselves to individuals, and greater workforce flexibility.

The importance of local authorities’ influence

It was apparent that one of the main factors explaining the variation in priorities of the health organisations we spoke to is the experience of their local authority partners. Almost all of the organisations who saw personal budgets as a high priority commented that their local authority has been instrumental in generating much of the interest and expertise to make this possible. The importance of local authority interest is further supported by the correlation which can be observed nationally between areas with higher than average use of personal budgets for social care and those where the PCT applied to pilot them through the Department of Health or Staying in Control. It may be that this link with keen social services departments will be a key determinant of the patterns in adoption of personal health budgets in the future.

Cost

With the coming squeeze on resources in the health service, the interviewees' scepticism over claims that personal budgets might save them money stand out starkly. Our research shows that a large majority expect them, if made mainstream, to require significantly more resources than current models of provision. The main reasons given for this were double running costs, administrative capacity and a rise in demand from previously unmet need. There was no clear message from the social care interviewees on what impact introducing personal budgets had made on their finances.

At a time when NHS organisations are under increasing pressure to restrain spending, most health leaders are unlikely to take personal budgets seriously if they see them as an additional spending commitment that does not save money elsewhere in the system. According to the Department of Health, personal health budgets should "help people get a better service from the NHS without it costing

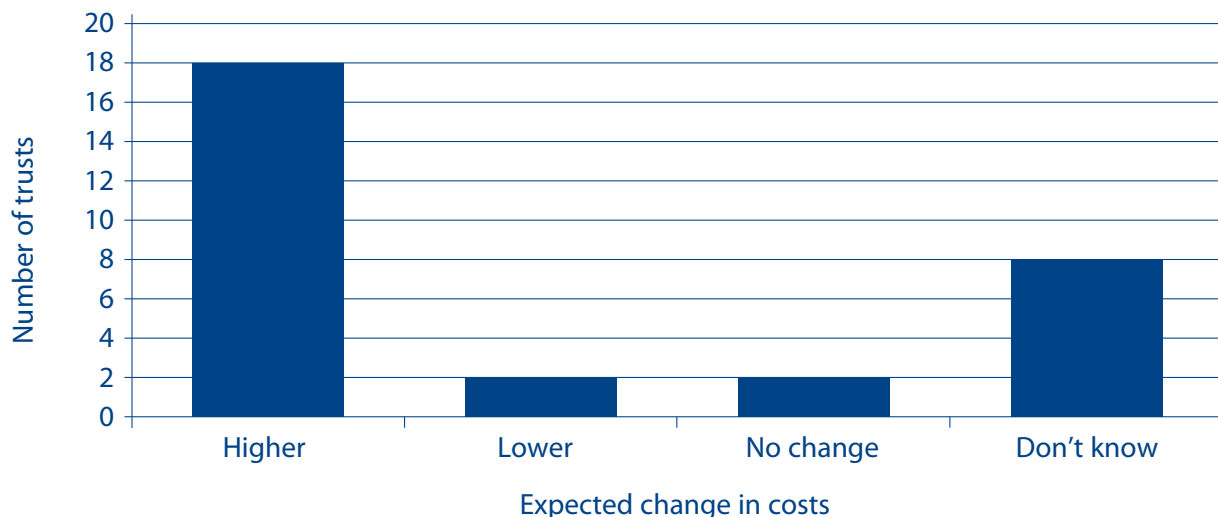
more."⁸ It should therefore be a matter of significant concern for proponents of personal budgets that their arguments for their cost-effectiveness seem to have been unconvincing. Many interviewees were aware, both from the IBSEN national evaluation and from local partners' experiences, that average social care spend is generally comparable or slightly lower in the areas in which personal budgets have been implemented. However, they did not believe these savings would translate to the health service.

Asked why this would be the case, there was strong correlation in their responses around three key areas: double running costs, administration and increased demand.

Double running costs

Unlike other service redesigns in the NHS' history, such as the transition from long-stay mental health hospitals in the 1980s, implementing personal

Figure 2. How do health leaders expect the costs of personal health budgets to compare to their current costs?



Source: NHS Confederation interviews

budgets will not entail closing a service and simultaneously transferring users to a parallel system. Rather, users will gradually opt to leave unpopular services and control their own care. This means that for an indeterminate period trusts will have to continue funding the fixed costs of their existing services as well as the personal budgets of those users who have left.

“The voids in funding which our local authority experienced when people left residential services after getting personal budgets were very difficult to manage, because until that tipping point is reached you’re double running.”

PCT chief executive

Leaders fear this will leave them with two equally undesirable options: either allow costs to rise, or allow the quality of existing services to fall. The worst-case scenario, envisaged by some leaders, would be having to close existing services before the tipping point is reached, with the net result being an overall reduction in choice, even for those on personal budgets. Users would have control of their care, but would have fewer options than they did at the start.

The problem of double running costs may be a medium-term one. If users generally choose cheaper packages of care, after some years the NHS would start to realise savings from personal health budgets. However, in the current climate the strength of even temporary cost increases as a disincentive should not be underestimated.

Administration

Fears of prohibitive complexity and cost in changing the commissioning, contracting and financing systems of local health organisations featured in half of provider and PCT groups’ top three ‘barriers to personal budgets.’ Moving from the current method of mostly block contracts between PCTs and providers, to thousands of individually allocated and administered budgets, would doubtless be a costly process in terms of training staff

and the capacity of finance departments. Depending on the level of additional administration required of front-line staff, these costs could result in an overall reduction in time spent with patients. This would particularly be a risk if, as some leaders feared, personal budgets gradually become more heavily regulated once they mature from pilots into the mainstream.

“The transaction costs are potentially enormous.”

Provider chief executive

It was widely felt that social services departments are more advanced in their finance and contracting systems and are capable of adapting to the demands of personal budgets with greater ease than the NHS. Many of the PCTs enrolled in the personal budgets pilot are receiving advice and support from their local authorities, and they noted how important this has been.

Increased demand

Even if average spend per patient does not rise in health, many leaders believe that total costs could still increase significantly through higher demand. As is the case in social care, there are many people with health needs in the UK who do not seek treatment. In mental health alone, the Royal College of Psychiatrists estimates that around 3.1 per cent of the adult population – around 1.5 million people – have a diagnosable mental health problem for which they do not receive treatment.⁹ While some of these people may feel they do not require care or are happy funding it themselves, it is likely that many recognise their need but find that the services currently available are not right for them. If the option to have control of a personal budget existed, however, many of these people could legitimately apply for one, with the effect being, as one chief executive put it, that overall costs would “sky-rocket.”

This is not a risk that can be modelled or predicted easily. Unless a certain level of public awareness of

personal budgets is reached, demand from unmet need will not rise noticeably. Pilots are therefore unlikely to allay leaders' fears on this issue. The best indicator is likely to be social care, where significant unmet need also exists and which is more developed in its use of personal budgets.

It should be remembered that increased demand on health services from currently unmet mental and physical needs might generate substantial public benefits, not only by preventing the development of more serious conditions, but also through indirect savings via higher employment rates, lower absenteeism and reduced crime. However, at a time when the NHS is focused on promoting more self-management of health conditions, encouraging a culture of widespread dependency on non-essential treatments was seen as a controversial route forward.

Are personal health budgets worth it?

Although there was a clear consensus amongst health leaders that they expect personal health budgets to increase costs, and widespread agreement over the reasons for this, attitudes to these risks varied. For some the severity of financial risk outweighs the potential benefits to service users, leading to little or no enthusiasm to pilot personal budgets without first seeing evidence that their fears are unfounded. For others, including providers and commissioners, higher costs or lower income were accepted as worthwhile if the improvement in health outcomes that they anticipated are realised.

"I think [personal health budgets] will give us problems, but if it makes people's lives better then we have to think of ways to live with that."

Provider chief executive

Case study: NHS Waltham Forest

NHS Waltham Forest has a history of close partnership working with its local authority, including joint health and social care teams for mental health, learning disabilities and physical disabilities. Its chief executive, Sally Gorham, feels closely involved with the council's ongoing work to develop direct payments and individual budgets. This experience has given the PCT an opportunity to see for itself how personal budgets might function in the NHS.

In principle, Sally thinks the benefits of personal budgets could be substantial, potentially with many patients' outcomes improving if they felt more in control of their care. This could have positive effects such as better concordance to treatment regimes, which patients would feel they had chosen rather than been 'prescribed.'

Despite these hopes for the potential of personal health budgets, the PCT does not feel ready to begin piloting them until it is clearer what the implications for the health system would be. As a PCT which already needs to control its finances very tightly, the unknown costs associated with running such a complex new system are a significant risk.

The local authority has already seen pressures on some of its in-house services as users who are given control gradually opt out, while the fixed costs of the service remain. "Until you get to a tipping point where nobody is using the service", says Sally, "there are voids left in the funding which are very difficult to manage."

With more robust modelling of the impacts of personal health budgets, NHS Waltham Forest would consider trialling them in some areas of long-term condition management. However, unless the discussion of their use takes the need to put in safeguards around the financial risks much more seriously, the PCT does not feel it is in a position to start trialling personal health budgets, in spite of its optimism that they will have a positive outcome for users.

Staff

Staff issues were the most common challenge raised, featuring in the top three expected barriers for more than half of the health leaders interviewed. Truly personalised healthcare would entail a huge cultural shift for the NHS, and its staff were felt to be a tough audience to convince. The experience of early implementers may give cause for hope, however.

To work effectively, personalisation needs the support of staff. Many of the benefits it could deliver rely on aspects of care which cannot be brought about by managerial writ, such as creativity, listening and user empowerment. Without staff engagement even a well designed personal budgets system will only appear to devolve choice and control to users, making it a hollow exercise.

It is notable that 56 per cent of provider and 46 per cent of PCT interviewees included staff issues as one of their top three barriers to the implementation of personal budgets. Many of the sites planning to be pilots had experienced difficulties already, ranging from apathy to outright resistance.

Few interviewees thought worries over job security or working conditions would be the primary point of resistance. Rather, it would be clinicians' fears for patient safety which would be the major difficulty. Health professionals are trained to follow evidence-based practice and are rooted in a culture of 'safety first' going back to the Hippocratic oath. Shifting to a system which may entail having to develop personal treatment solutions for which there may be no evidence or which a clinician may see little value in will be a huge challenge.

"It will be hard to go from 'doing to' to 'doing with'."

Provider chief executive

The social care experience

The fears of health leaders that their staff will be a major challenge in implementing personal budgets are well founded, according to our sample of social care leaders. All but one of this group named the shift in service culture as one of the top three barriers they had experienced so far.

"We have trained [our staff], inadvertently, to be very risk averse and paternalistic over the years – to go in quickly, sort the problem out and move on. One of the challenges of personal budgets is that you have to engage much more in a relationship."

Director of adult social services

The tone of these concerns was different to that of the health group, however. The additional years of experience training their staff to see the benefits of personal budgets, often with considerable success, appeared to have produced a more optimistic assessment of the scale of the problem. Many leaders shared stories of initially encountering significant resistance and scepticism across their organisations, which then rapidly dissipated as people began to observe the positive results that personal budgets produce.

"A lot of staff felt that it freed them up to do real social work, and we've stuffed that out of them over the years."

Director of adult social services

Some social care leaders acknowledged that health staff are likely to be a less receptive audience than social workers. This is not only because the NHS is perceived to be more professionalised, as noted above, but also because in social care there is a clearer understanding of personalisation as a strategic direction. The introduction of personal

budgets to social care has had much groundwork laid by other reforms such as personal-centred planning, dignity in care and direct payments. These have helped to create a familiar narrative for social workers into which new initiatives such as personal budgets fit with greater ease than if introduced in isolation.

Despite the additional challenges perceived in the NHS workforce, the experience of the early adopters in social care appears to be that while staff engagement should be the principal focus of any attempt to introduce personal budgets (see page 18) the problem is not insurmountable.

Case study: Lincolnshire Partnership NHS Foundation Trust

Lincolnshire Partnership NHS Foundation Trust began its involvement in individual budgets through a joint initiative with Lincolnshire County Council in 2006. The council was one of the original 13 pilot areas for individual budgets and now has one of the highest numbers of personal budget holders in England.

The pilot involved giving individual budgets to 30 people with serious mental health problems in the East Lindsey area. Many of these people were highly dependent on the service and had been receiving treatment for some considerable time.

The outcomes of the pilot were very positive. The trust found that it was able to achieve significant improvements to wellbeing with relatively small amounts of money. Those involved in the pilot used their new flexibilities creatively and chose sensibly. As a result, service user experience was considerably better than beforehand. This year, the project's mental health team won a Community Care Excellence Award for their achievements.

Lincolnshire Partnership feels its involvement with the council's pilot has given it valuable experience of managing personal budgets within a mental health setting and is keen to develop this by expanding their use. While it is working to reach 30 per cent of its social care users on personal budgets by March 2011 (NI 130), in health it is more cautious, describing its approach as "reform not revolution."

Paul Jackman, Head of Strategic Partnerships at the trust, says that coordination between local health and social care bodies is essential if personal budgets are to be brought into the health service effectively. Failing to do so risks a lack of alignment between what service users want and what is available, potentially leading to double running costs or services having to close while there is still demand for them.

One of the key lessons the team have learned so far is the scale of the cultural challenge that introducing personal budgets entails for their trust. Bob Marshall, the partnership's personalisation lead, comments that moving from a "professional gift" model of care to one that truly empowers users requires a change of mindset at every level of the organisation. Commitment is required from leaders and practitioners, he says, who can struggle with the idea of giving up some control to users. Equally, it can be difficult at first to convince front-line staff that personal budgets are much more than a paper exercise.

Users

The social care leaders we interviewed reported that local service user reaction to personal budgets has been very positive. Despite this, both they and the health leaders expected the NHS' experience would be different. Patient groups were reported to be interested but cautious and it was thought unlikely that the personal budgets agenda would be driven by popular support and pressure from users and carers, as was the case in many social care departments nationally.

Although none of the health organisations we spoke to had conducted formal consultations on this issue, it was felt that demand was primarily for more flexible, person-centred care, with little interest in the mechanism used to deliver this. Users would rather have such services provided directly to them. However, with this not being available in many cases, the option to manage it themselves would be broadly welcomed.

"If you have really good self-determined care, with care navigators standing beside people and helping them navigate services and get what they want, you find that quite a lot of people don't want the bother of managing their own budget."

PCT chief executive

Only a minority of interviewees expected significant resistance to personal budgets from

service users, mostly due to them being suspicious that it is a route to closing services or cutting costs. Challenges will exist, however, and many leaders with experience in implementing personal budgets commented on the need for patience and acceptance that most of their budget holders will initially act conservatively and require reassurance. This was supported by those with experience of developing personal budgets in social care, some of whom described an often lengthy process of getting users past a dependency mentality to feeling able to control their own care.

Safeguarding

Most health leaders foresaw personal health budgets leading to future dilemmas over safeguarding. The majority of these were concerned that allowing patients unprecedented freedom to decide the nature of their care will lead to them supporting poor choices in some instances that would result in harm being done. Some raised questions about whether clinicians or NHS trusts themselves might be liable in such circumstances.

Various leaders from the provider group also raised concerns around regulation. Logistically, the transition to a market of thousands of micro-providers would be impossible to administer if current safeguards remained. To accommodate

the plurality of the market, legal requirements would have to be relaxed, leaving room for quality to deteriorate. Some local user advocacy groups have expressed anxiety that this will leave room for unscrupulous individuals to exploit the vulnerable. One worst-case scenario envisaged by two mental health providers is where a low level

of assurance is demanded for micro-providers (something akin to the childminders register) whilst current regulation of their organisations remains. This would effectively result in micro-providers being able to undercut large trusts because the overheads required for quality assurance did not apply to them.

Offering choice in mental health

Mental health providers were unequivocal in stressing that if personal budgets do become widely available in the NHS, their services should not be excluded.

The variable capacity and potential for rapid deterioration that exist with many mental health conditions creates particular challenges when offering greater choice and self-determination. Contingency plans for what should happen if a budget holder goes into crisis are an important step for the peace of mind of both staff and user. Several providers pointed out the importance of remembering that offering a personal budget is not a one-way road, but a sliding scale along which service users can be shifted according to their capacity.

What lessons should the NHS learn from social care?

There was a broad correlation between the challenges anticipated by health leaders and those that are already being faced in social care. While the NHS will ultimately have to find its own unique solutions to these, there are several key lessons that the social care leaders we spoke to said the health service should take from their experience.

Asked to name the main barriers to developing personal budgets they had faced, the issues named by the social care interviewees showed a strong correlation with the concerns of health leaders outlined throughout this report.

Tackling opposition from service users and staff, establishing complex new procedures and infrastructure, developing their provider market and coping with up-front costs all featured consistently. Asked to give the key lessons they had learned from these experiences, five main messages emerged, outlined below.

Lesson 1: Culture, not mechanism, is the real challenge

Staff engagement needs to be the first priority for any organisation hoping to trial personal budgets. It would be entirely possible, our interviewees said, to establish flawless procedures and mechanisms and never offer users any more choice than before. Similarly, many felt – and are experiencing the reality – that with fairly rudimentary and untested systems, but with passionate staff, personal budgets can be transformative.

How staff are made to feel about personal budgets will determine how they are presented to patients. It should therefore be the priority for those organisations planning to pilot personal health budgets to involve clinicians from the outset, and to dedicate a substantial share of any resources into training.

Lesson 2: The importance of story-telling

While our research shows health leaders are primarily interested in evidence, not anecdote, to convince them of the potential of personal health budgets, we should not assume that staff think the same way. According to our social care leaders' experiences, the most effective strategy in building momentum behind personal budgets has been allowing staff to see the benefits first hand, as early as possible, preferably from the budget holders themselves. Health leaders should therefore look out for stories of the effects of their trials on patients' lives from the very beginning and make sure these are spread.

Lesson 3: Volunteer value

Many of the solutions to the barriers faced by our social care interviewees have come from the third sector. Local voluntary and user-led groups can add significant value to personal budgets schemes, and in areas such as brokerage, staff training and direct service

provision they can often offer something unique, frequently at a lower cost.

Lesson 4: Partner in personalisation

The importance of a local authority's influence around personal budgets, highlighted on page 9 of this report ('How high a priority are personal health budgets?'), confirms the social care leaders' belief that partnerships are key to personalisation. Managing a strategic local response to personalisation should be a priority for local authorities, PCTs and health providers. Even when the health organisations in an area do not want to take personal budgets forward themselves, they should coordinate with their social care counterparts to learn as much as possible from their experiences.

Lesson 5: Be brave!

Health leaders are right to be cautious given the risks that they believe personal health budgets can bring. Nevertheless, those organisations with high numbers of personal budgets in social care encouraged them to show courage in promoting innovation in their own organisations. Above all, it is important to maintain perspective of the strengths and weaknesses of current health systems while assessing those of personal health budgets. Health leaders should not expect this new model of care to be faultless before they consider it superior to present practice.

"Whilst we're happy with a system that delivers poor outcomes at high cost, we seem to want to have every last reassurance about the alternative before we'll take a step forward."

Director of adult social services

Viewpoint

This report is intended as a contribution to an issue of growing importance to the future design of the NHS. The opinions it represents belong to a sample of individuals and therefore cannot with certainty be said to reflect the whole. Our scope did not extend beyond speaking to a proportion of relevant organisations and, for the most part, only the views of the most senior staff in those organisations were sought.

Reflecting on the messages we heard most consistently from our interviewees, it is our view that there exists at present a danger of a growing divide between policy and practice. Personal budgets appear to be increasing in their prominence within central government's vision for the future of the NHS, yet at the same time most local health leaders remain unconvinced. These key individuals, who will be vital to any efforts to make personal health budgets a reality, currently see them as too immature to be considered a serious priority. Their concerns, which they say must be taken much more seriously in future discussions if they are to be convinced, have been outlined in this report.

Although we found that consensus has progressed significantly in recent years, in that there is now

widespread acceptance of the potential of personal health budgets, there is a long way to go if this is to be exploited. National pilots are an important development and will help to build an evidence base on which leaders can make more informed decisions. However, the scale of transition required means that local leaders need to be working with their managers and clinicians now if they are to prepare the system to be ready within the foreseeable future.

Finally, we share the view expressed by early implementers that introducing personal health budgets in isolation from other means of self-directed support will severely limit their potential. Instead, they need to be seen as one part of a wider set of tools for personalisation. Given health leaders' support for this as a strategic direction, they would be wise to ensure they are developing the many other means of offering patients more choice and control, irrespective of the forthcoming pilot programme.

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

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Shaping personal health budgets

Personalisation is a key aspect of future health policy, but how close is it to becoming a reality? Personal health budgets are at a critical stage in their development as they move from theory into practice, and are currently entering the pilot stage. How local leaders shape and interpret this transition will be decisive to the success or failure of this new, innovative model of care.

This report presents the opinions of local health and social care leaders on the future of personal health budgets. It portrays their understanding of the key issues, as well as their expectations, hopes and doubts. Our research took a particular interest in mental health services, but the findings are relevant across the NHS.

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