Personal health budgets

The shape of things to come?
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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 Shrubb on 020 7074 3217 or at steve.shrubb@nhsconfed.org

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Developing responsive and individual packages of care will drive up the quality of care provided to people who have a range of needs.

Before piloting gets fully underway, we need to consider the commissioning, funding, staffing and service design issues associated with developing personal health budgets.

The NHS Confederation has found a consensus that urgent and emergency care and elective procedures, already delivered through tariff, should not be part of personal health budget calculations.

Some operational issues still need careful consideration, for example whether NHS money could be spent on non cost-effective treatments such as high-cost medication or alternative therapies.

Personal health budgets could improve personal control, empowerment and cost-effectiveness, and could provide better coordinated services, greater choice and new ways of redesigning services.

Evidence from Germany, Holland and the USA shows that there can be advantages for health in the personal budget approach.
Introduction

NHS reforms can be said to have delivered well on episodic experiences of care where the benefits of improved choice and the NHS market have led to improvements in access and waiting times. However, many people with disabilities or long-term conditions need continuity and coordination of care from different services and agencies to meet a range of needs which are very personal to them.

Driving up quality in this area requires developing responsive and individual packages of care and involving recipients much more in the design, delivery and on-going evaluation of them. Developing patient reported outcome measures (PROMs) may enable better evaluation of the care provided, but the real transformation, particularly in long-term conditions, including mental health, requires a different relationship between the professional and the cared for person in terms of both planning and delivery.
Successive Secretaries of State have championed improvements in choice and personalisation of health services. This is also a current area of overall consensus between the two main political parties.

In the 2006 white paper, *Our health, our care, our say*[^1], the development of personal budgets in healthcare was dismissed as “compromis(ing) the founding principles of the NHS that care should be free at the point of use.” This, despite the fact that similar personal budgets and direct payments have been available in social care for several years, albeit for a relatively small number of the recipients.[^1]

By the time of the NHS Next Stage Review in 2008[^2], the Secretary of State for Health endorsed the proposal to include NHS funding within personal budgets, allowing people “to choose support which ensures their well-being and enables independent living.” Services put forward as potential pilots include NHS Continuing Healthcare, mental health services and long-term conditions. Indeed, universal services such as maternity and therapy services have also been suggested.

Two recent papers have warned that if individual budgets only apply to social care, “then the potential power of personalisation is diminished”[^3] although “individual budgets could weaken the NHS.”[^4] It is, therefore, timely to consider further the key issues around the development of personal health budgets before piloting gets fully underway.

This report follows two seminars, one held with key opinion leaders and one with NHS Confederation members. It is designed to explore the potential of personalisation and stimulate further debate on how this development will impact on mainstream commissioning and provision of NHS services. The first half of the report sets out what we mean by personalised health budgets and what we already know about them. The second half explores the possible impact on the existing healthcare system and what still needs to be considered.

[^1]: In 2006/7, 48,000 of the 1.52 million people in receipt of social care received direct payments – one manifestation of personal budgets – an increase of 28 per cent on the previous year but still only a small proportion of the total.
Definitions

There are many different terms used when discussing personal budgets. Clear definition is important to avoid confusion.

**Direct payments**
Direct payments are means-tested cash payments made to individuals who have been assessed as needing services, in lieu of social service provision. Councils must make a direct payment to eligible individuals who are able to provide consent, and direct payments should be discussed as a first option at each assessment and each review.

**Individual/personal budgets**
With individual budgets, patients are given control over a direct payment or an indicative fund of money for their treatment, either directly or through an advocate or care coordinator. Users can use the budget to form care packages that suit their own needs.

They are not the same as ‘personalised/individual budgeting’ or ‘year of care’ models, which aim to incentivise providers to focus more on prevention by paying them a fixed sum of money for a given individual based on knowledge about their condition.

**Self-directed support**
Self-directed support is an overarching term used to describe what In Control characterises as a seven point plan developed by the care user with professional support: agreeing a sum of money; making a support plan; getting the plan agreed; organising the money; organising the support; implementing the support plan; evaluating its effectiveness.
The benefits of personal health budgets

Elements of personal health budgets are already being piloted through the Staying in Control project, involving 34 primary care trusts (PCTs) in England. In Control – the body running the pilots – argues that personal health budgets will work well in areas where health and social care work closely together but that the money, whilst important, is only one element of the wider move to self-directed support. It believes that this will transform some elements of care delivery, particularly in long-term conditions and mental health.

The potential benefits of personal health budgets are outlined below.

**Improved personal control and empowerment**

The Department of Health report on choice and personalisation\(^5\) states that:

> Giving people a greater choice over their care… places patient control and empowerment at the heart of effective care planning and encourages participation in self and shared care, strengthening partnership between users, patients and clinicians.

The report states that the key to success is active and intelligent commissioning as people are more likely to access services which they believe reflect their needs and aspirations. Evidence from the Picker Institute shows that patients involved in shared decision making are better informed, more engaged in decisions, more in control about the direction of their care and treatment and more likely to have better health outcomes.

**Greater choice and responsiveness to need**

If services are designed by the individual, their responsiveness should be dramatically improved and the choice of service will be limited only by what can be purchased from the market or ‘made’ through a tailored care package.

**Improved cost effectiveness of complex or coordinated services**

Costs may be reduced as patients are more likely to participate fully with a co-designed service, so reducing wastage, and specify only what they need.

**Improved recognition and coordination of a single experience**

Evidence from the *Your health, your care, your say* consultation\(^4\), patient experience surveys and work undertaken more recently by the Local Government Association\(^7\) show that individuals do not recognise the barriers in care delivery that exist in the current system. They expect health and social care to be provided as an integrated package putting their personal needs centrally. The lack of integration and coordination of services is a key source of discontent and leads to services being seen as inflexible and unresponsive. Integrating services through personal commissioning reduces the barriers, clarifies accountability and changes the emphasis of services to a more person-centred mode of delivery.

**A new approach to service redesign and transformation**

This change in empowerment can also change the dynamic between the professional and the patient. The centrality of the patient experience may change, on a macro as well as individual level, the way in which services are designed and delivered.

A Department of Health report in 2004\(^8\) suggested that improving self-care could decrease length of stay in hospitals for mental health, reduce A&E visits for asthma patients and halve the number of sick days for people with arthritis. The NHS contributed an estimated £3 billion of resources towards long-term care in 2003 and, by 2005, 22,000 people had their personal care costs fully funded by the NHS.
International experience

Whilst the differentiation of the experiences in health and social care is important, in other European countries, for example Germany and Holland, there is more systematic experience of personal care budgets than in the UK.

Germany

Germany’s social insurance model has been in place since 1994 and gives care benefits in the form of cash, formal services or a combination of the two. Whilst only around half of the value of the formal services, receiving cash payments has persistently proved to be a more popular option.

Glendinning9 highlights a number of lessons for the NHS from the German experience:

- Support is guaranteed for all eligible people regardless of geographical area or financial circumstances, whereas provision in the UK can be very uneven (as a result of the eligibility criteria for social care used under the Fair Access to Care Services system).
- Standardised assessment processes are transparent and avoid discrimination against certain groups, for example older people with family carers.
- Separation of long-term care budgets from mainstream health expenditure mitigates the risk that the former will be squeezed.
- Central government plays a key role in overseeing funding. Glendinning advocates the UK government becoming more involved in pooling all available resources and managing allocations to address inequalities.
- Family carers in Germany have their pension contributions met by the state, so supporting them in their caring role.

Holland

The Dutch personal budget has been in place since 1995 and is heavily regulated. In 2003 there were 65,000 budget holders. Examining this, Monique Kremer10 commented that it provides the individual with autonomy from health professionals and enables them to “own the definition of good care.” However, the Dutch experience has been that the market for care provision has been slow to develop, with mergers over time reducing the scope for competition. Consumers have also become dependent on the support of care consultants to manage their care, reducing their autonomy from professionals. Kremer says: “The problem is that the quality of care is not only a matter of consumer choice but also heavily dependent on the qualities of the caregivers.”

The USA

In the Cash and Counselling programme in Florida, money is allocated on a budget rather than cash basis, which has delivered a wider uptake by patients. The funding is held by a third party. The links to managed care programmes can be complex but the potential for fraud and/or abuse has been found to be much less than anticipated. In this programme the patient draws up their spending plan in association with their counsellor but the spending has to be approved by the state before the programme is fully implemented.

‘Dutch consumers have become dependent on the support of care consultants, reducing their autonomy from professionals.’
A report, published in January 2008, looked at the Empowerment Initiatives Brokerage in Oregon and highlighted a range of benefits and challenges associated with it. Its conclusions were that personal budgets could deliver some significant changes in the system:

- the empowerment of service users
- a change in the role of the professional from director of care to advisor
- an increasingly diverse range of locally-held knowledge provided from the range of individual experiences
- flexibility and decentralised provision on the supply side, with providers having to work harder in order to secure resources.

Other work reported in June 2007 estimated that at least a quarter of the existing mental health budget could be placed in the hands of individual patients (compared with 0.1 per cent at the time of writing). Using evidence from the USA and social care in the UK, it again outlined several benefits, including:

- greater personalisation
- the potential to alleviate capacity concerns
- stronger coordination for those who rely on a variety of services
- more transparency in the allocation of NHS resources
- improved value for money – in a Massachusetts programme, spending on clinical and social services decreased by 78 per cent between 2002 and 2006.

'It has been estimated that at least a quarter of the existing mental health budget could be placed in the hands of individual patients.'
Impact on the current system

The social care experience

An evaluation of the Individual Budgets (IB) Pilot Programme in social care, published in October 2008, found that IBs were generally welcomed by users but that their impact varied between different user groups. Budgets were used to purchase personal care, assistance with domestic chores and social, leisure and educational activities. Whilst costs were comparable to conventional social care costs (on average, £280 per week as opposed to £300 for conventional services), satisfaction was highest for mental health users and the physically disabled and lowest among older people. For this latter group, IBs were found to be associated with lower psychological well-being, possibly as they felt the processes of planning and managing their own support were burdensome.

In the Department of Health’s response to the report, the commitment to piloting the health input into personal budgets was restated:

Research suggests… that once barriers are overcome, with the right support and culture change, direct payments are a positive option for many older people, giving them greater choice and control and improving their quality of life and their emotional, physical and social health.

It is clear, therefore, that there are several potentially challenging impacts on the existing NHS system.

Commissioning systems

Clarity of roles

Any system of personal health budgets needs to be seen in the context of existing tiers of commissioning activity within PCTs. There must be clarity between the roles and responsibilities of the PCT, the practice-based commissioner and the individual in commissioning their own care either directly or through a co-produced care plan.

Commissioning models

Personal health budget holders may well request a different range of service delivery models, tailored to their individual needs but not necessarily in line with those conventionally commissioned by practice-based commissioners or the PCT. This could have two different but important implications.

Firstly, the present market for healthcare may not be configured in a way that supports the delivery of self-directed healthcare and support. The development of existing markets needs to take into account the differences in services required for those who need personalised care packages.

Secondly, the market must be balanced with services delivered to those who choose not to take part in or whose care is not amenable to self-directed support. Whilst it could be argued that personalised service models should benefit all, there may be a tension between the PCT and personally procured services. Care will be needed to ensure that positive incentives for personal health budgets do not appear coercive for those who feel less confident to manage their own care. Commissioners will have to consider whether the levels of advocacy are sufficient to ensure individual patients are supported in their decision making without increasing the cost of services as a result.

Funding

Designing the budget

The design of personal health budgets will be critical to their success. Some elements can be based on existing systems – for example, the needs
assessment used in determining NHS continuing healthcare entitlement – but issues remain about the consistency of assessment and what should be included or excluded from the determinations. Our work has suggested a consensus that urgent and emergency care and elective procedures, already delivered through tariff, should not be part of personal health budget calculations. However, the inclusion of other elements of care, for example sitting services that enable the patient to live independently, will need to be carefully considered.

Resource allocation
The question also remains as to whether existing resource allocation systems are sufficiently developed to reflect the subtlety of individual needs in calculations. There will be a requirement to understand in detail the cost of services and the price of individual interventions, particularly if the budget is to be real rather than indicative. This may be a particular issue if money is to be released from the budget, for instance for the payment of informal or family carers.

Budgetary flexibility
Will it be acceptable for NHS money to be spent on non cost-effective treatments, for example high-cost medication or alternative therapies? And can the individual top up their NHS budget with their own funds, particularly where they are in receipt of both health and social care funding? The differentiation between what can or cannot be topped up may become blurred over time. Similarly, clarity will be needed on whether budgets can be invested against future requirements and whether cumulative budgets stretching over financial year ends will be acceptable.

Transaction costs
There is little evidence at present of the extent of the transaction costs that will accompany the development and implementation of personal health budgets. This is a particular issue where navigational services may be commissioned to support recipients or where the aggregation of individual commissioning decisions has to be added to existing systems for those elements of care still being funded through tariff. There is the potential for double running costs for some services where both a personal and block contract approach is necessary. Care will also be needed to ensure that there is no cost shunting, so that the funding sources can still be identified for governance and accountability purposes.

Risk

Risk for the individual
Much has been written about the implications of direct payments in social care on the assessment and management of risk in the system – in particular, how to ensure that the money is appropriately used and that personal safeguarding arrangements are robust, for example where personal assistants are employed. For personal health budgets this is also an issue, with questions about how appropriate such budgets are for unstable or unpredictable conditions or elements of care. There is a need to ensure that individuals have sufficient support to deal with the consequences of their decisions, for example about employing personal assistants to do part of the caring.

Risk for the development of the supporting system
A second set of risk issues is associated with the development of the model of care. The policy will need to develop over time, with early versions potentially less successful in meeting needs holistically. In the interim, there may be issues with the risks in the policy both from a financial and reputational perspective.
Service design

The services to be included
Recent discussions have focused on which areas of healthcare might be used to introduce personal health budgets. Four questions, developed by Professor Jon Glasby and others, may be helpful in putting this in context. These suggest that personal health budgets are most useful where:

- the budget would help improve care planning
- there is scope for the budget to drive innovation and enable creativity and flexibility
- personalisation has a profound impact on the individual, for example end-of-life care, mental health or maternity services
- benefits outweigh the likely transaction costs.

However, there must also be an understanding that personal choice includes the legitimate choice not to request a personal budget.

All or nothing?
Another important consideration is whether some elements of care can be personalised or whether a personal health budget can only apply to a whole package of care. In either case, the development of robust information systems is needed to ensure that individual choices are well informed and the limitations of the budget and amount of support available to help with administrative parts of the process are understood.

National tools and support
In social care, present discussions centre on the acceptability of a national resource allocation formula or RAS as recommended in the CSCI report on eligibility criteria, *Cutting the cake fairly* 15. For personal health budgets, a similar tool would need to be developed and a sound and consistent structural framework would have to exist at national level to enable consistency in application.

‘The effective delivery of self-directed care and personal health budgets is dependent on the development of a different relationship between the professional and the individual patient.’

Evaluation and evidence
The evidence basis of the effectiveness of some healthcare interventions in long-term conditions is still weak and the development of personal health budgets needs to be accompanied by robust evaluation of what works and what does not when delivered in this personalised way.

Staff

Local leadership and ownership
The effective delivery of self-directed care and personal health budgets is dependent on the development of a different relationship between the professional and the individual patient. To introduce this will require changes in the way in which professionals see their role to one of enablement, co-creation of care packages and ongoing support and advocacy. Local leadership will be needed to support this change and ensure that the cultural changes that may be needed are implemented and re-enforced over time. The buy-in of senior management locally will be crucial in developing and delivering the change.

Cultural shifts take time
Our seminar participants were clear that delivering sustainable change takes time. More than one iteration could be needed before a lasting workable model is in place and support from Government would be necessary so that pilots can run their course before being implemented more widely.
The role of clinicians and the lead professional
Personal health budgets will move the balance of control in the professional/patient relationship towards one of co-production of care plans etc, and the impact of this on clinical practice should not be underestimated.

Care will be needed to ensure that clinicians are fully involved in the changes and the implications of these for their own practice. A similar issue concerns the lead professional or care navigator and the necessity, or not, of this role being played by a clinician.

System issues

Implementation issues
The phasing of the introduction of personal health budgets should be a key part of any strategy, given the implications. There will need to be a clear recognition of the structural framework, for example of assessment tools etc, and the possible pace of change to ensure that this is in place in good time to support implementation. Evidence from social care has shown slow uptake initially, with an increase in pace over time as people become more aware and confident to take up the opportunities personal budgets present.

There will also be a requirement to understand areas where the social care evidence is clear and where there will be differences in what is required for health to participate fully in this system change. Our seminar participants believed that care should be taken to ensure that personal health budgets are not seen as a solution to a range of problems. Rather, their focus on improving personal control should be seen as key.

Impact on health inequalities
Evidence has shown that increased choice and the development of empowerment models can differentially support people from more disadvantaged communities if targeted appropriately. However, any implementation should evaluate impacts to ensure that sufficient support is available where necessary to improve uptake in harder to reach groups.

Working in partnership
The major gains for the system will be realised when:

- the health and social elements of a personalised budget are aligned for an individual so that integrated services can be commissioned and procured
- the flow of funding from personal health budgets enables a range of health providers to deliver care in a seamless way.

Both of these outcomes will require partnership arrangements that are robust and work well even when resources need to be commissioned across several organisational boundaries.

‘Care should be taken to ensure that personal health budgets are not seen as a solution to a range of problems.’
Principles for implementation

Many of the issues outlined on the preceding pages will need to be explored through the piloting process, but our work suggests that there are some principles deriving from them that should be used to support the development of personal health budgets.

**Strategic, structured evolution**
Implementation should be through managed change and innovation with appropriate lead times to enable a thorough evaluation.

**Language and definitions are important**
Clarity of expectations will depend on clarity of understanding of what can or cannot be delivered and the timescales needed to develop the infrastructure to support personal health budgets.

**Personal health budgets won’t work for everyone all of the time or for the whole of the care package**
An all or nothing approach will remove choice.

**Culture is key to successful implementation**
“Implementing individual budgets required major shifts in staff and organisational culture, roles and responsibilities. Intensive support and extensive training will be needed, particularly in developing specialist support planning and brokerage skills. Greater capacity in managing budgets flexibly within care management will also be needed.” (IBSEN report13)

**Expectations must be managed – up and down**
The change will take time and a thorough evaluation of the pilots will be needed. This is a part of the overall commissioning landscape but not the complete answer. Personal choice will determine overall uptake and national expectations must take this into account.

**Local systems must work from a clear, shared values base**
Sustainable and coherent local systems will develop where commissioners and providers are working from a shared vision and set of values.

**Scope should be determined locally**
Whilst a national framework for assessment and resource allocation may have a central place in defining the process, the scope of implementation will depend on individual and local needs.

**Models should be tiered to enable choice**
Degrees of personalisation will be necessary to ensure ownership by individuals without any element of coercion.

**National and local frameworks must be permissive with broad criteria**
The innovative nature of personalisation will be lost if national and local criteria are too restrictive.

**Development of the evidence base needs to go hand in hand with the development of the system**
More work is needed to develop the evidence base for personal health budgets within the UK context. Evaluation and success criteria must be in place as the system develops to ensure that it can be refined over time to better suit individual needs.

**Models should not run on parallel tracks to standard pathways**
Developing the model of the personal budget as one element of a standard pathway will enable personalisation to be proportionate to the individual’s requirements for control.

**Commissioning processes need to reflect the move**
The development of the provider market should reflect the need to provide both standardised and personalised service options.

**Build the budget over time – omit some tariff-based services, for example elective surgery and urgent care**
It will take time to understand the elements of the budget subject to personalisation and the costing associated with certain service options. This will need to evolve so that, in the long term, a comprehensive menu can be developed. Where needs are not predictable, however, there is some consensus that tariff-based interventions, for example urgent care, should not be part of a personally held budget.
Conclusion: the impact of personal health budgets on the NHS

This report outlines the overall framework within which personal health budgets need to be considered and some principles which may be useful in scoping their implementation. There are some wider system issues that also need consideration and further debate.

The four key areas that remain for debate are as follows.

Will personal health budgets undermine the NHS as a universal and free service?
The service could potentially deny additional access to individuals who have already received treatment as part of their personal entitlement. Distinctions might be blurred between universal and means-tested services, which could further confuse the issues about topping up and the co-payments legally possible for the NHS.

Will they have an impact on NHS funding?
The possible ‘deadweight cost’ where NHS personal budgets are provided in areas where private expenditure is currently a significant funding source, for example podiatry services, could adversely affect NHS budgets overall. Restricting decisions would have to be more explicit. Restricting top-up payments could prove to be more difficult to enforce.

Are they legally possible on the NHS?
At present it remains illegal for the NHS to pay money directly to patients and this would require legislation to change. However, it is legal for the NHS to provide resources to a third party. The responsibilities of commissioners for money spent by patients would have to be clearly defined. The legislative programme for 2009, published in December 2008, includes a commitment to enable direct payments within health.

Will their implementation change the commissioning or provision parts of the system?
By separating those elements of care that are predictable, for example on-going support for a long-term condition, from those which are not, for example elective surgery or urgent care, the role of commissioning would change and market development would have to take those changes into account. In particular, the role of practice-based commissioning will need modification to focus more clearly on these elements which could be influenced, for example demand management for elective surgery, and away from commissioning for long-term conditions care, where procurement would be on the basis of an aggregate of individual choice decisions.

For providers, the offering of tailored packages of care would become a bigger challenge, in particular how the different elements of the package which might be delivered by different providers could be coordinated in a coherent and seamless way. Collaborations of providers would be more desirable and quality outcomes would need to be balanced by value for money incentives.

‘By separating those elements of care that are predictable from those which are not, the role of commissioning would change and market development would have to take those changes into account.’
In summary, the evidence from social care and internationally shows that there are considerable potential benefits from the development of personal health budgets. However, a balance needs to be struck between these and the potential impacts on an already changing system, particularly in the different roles in which clinicians could find themselves. What is clear is that the piloting phase will be crucial to a clearer understanding of the impact and a clearer set of principles through which this initiative could be developed. We hope that the ones suggested in this report can be used as a starting point in the debate.

We would welcome your views and suggestions on these and other issues raised. We will continue with this work during 2009 as the initial guidance for the pilots is developed.

If you have any comments on the issues raised in this report, or suggestions, please contact jo.webber@nhsconfed.org
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The 2008 NHS Next Stage Review endorsed the proposal to include NHS funding within personal budgets, allowing people “to choose support which ensures their well-being and enables independent living.”

Two recent papers have warned that if individual budgets only apply to social care “the potential power of personalisation is diminished” although “individual budgets could weaken the NHS”. It is, therefore, timely to consider further the key issues around the development of personal health budgets before piloting gets fully underway.

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