Personal Budgets as an integral form of NHS care: A discussion paper

December 2015
Summary

There is growing evidence that personal budgets can be an effective, valued and value for money mechanism to improve the quality of life of people with long term conditions, and their experience of care and support services.\(^1\) They give people greater choice and control over the support they access, ensuring that it is shaped around their lives and goals. People who have used a personal budget to access support report improved experiences and wellbeing.\(^2\)

Despite this evidence, some commentators have expressed concerns about the use of personal budgets within the NHS. Recent coverage has suggested that the support accessed through personal budgets can be inappropriate, dismissing them as allowing people to purchase ‘luxuries’.\(^3\) This has raised questions about the impact on existing statutory services given limited resources, and whether they are fully compatible with a universal National Health Service. It is feared that this could threaten the sustainability of existing services if funding follows budget holders who choose alternative support.

National Voices, Shared Lives Plus, TLAP and In Control believe that these concerns are misplaced, and reflect a lack of understanding of how personal budgets ensure that NHS funding is targeted so that people receive the help that best meets their health goals. Rather than trying to shoe-horn all patients with a particular condition into an existing service, whether or not they find it useful, people work alongside their clinicians to identify what will be most effective in helping them to manage their condition and live a full life.

We believe that the positive impact that personal budgets can have on the lives and wellbeing of people with long term conditions warrants their wider use across health and care, based on personalised care and support planning.\(^4\) Our view is that personal budgets are consistent with, and indeed strengthen the NHS’s founding values of health care that is comprehensive, collectively funded, and free at the point of use.

In addition, personal budgets can be implemented in a way that promotes collective action and community ties, rather than individualism and privatisation of health and social care. Most importantly, they have the potential to improve experience and outcomes for individuals, by ensuring that the care they receive fits around their lives and goals, rather than around the institutions that provide it.

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\(^1\) The Health Foundation (2010) *Personal health budgets: research scan* See Appendix for discussion of this evidence
\(^4\) National Voices (2014) *Care and support planning guide*
The key points contained in this briefing are that personal budgets:

1. Are a policy success story that has become consensus, and are valued by their users;

2. Add value to traditional statutory care, helping people to contribute more in a way which can reduce system costs and increase sustainability, and where properly used can be a new route for people to co-design statutory care services;

3. Offer personalised and effective support on the same basis as other NHS services: collectively funded through tax revenue, free at the point of use, and (potentially) available to all according to need;

4. Can be provided as well as funded collectively, through using a ‘social value’ approach to local commissioning, via voluntary and community sector groups and organisations;

5. Can stimulate the statutory system to raise quality and be responsive to user preferences;

6. Can promote equity, in that people without financial resources can choose to use sources of support that are otherwise only available to the better-off;

7. Have the potential to be driven collectively by users, through the development of pooled budgets and purchasing power.
Introduction

Personal budgets are an amount of money, funded by the NHS or through social care, which is used to offer individuals choice and control over their care, treatment and support.

Personal budgets can be implemented in different ways. Individuals may receive a direct payment equal to the agreed budget, which they use to purchase services themselves. Or the budget may be managed by statutory services or a voluntary sector broker, who purchase the services agreed on behalf of the budget holder.

The background to personal budgets is well known and has recently been summarised by TLAP, NHS England, the LGA and ADASS in ‘Getting serious about personalisation in the NHS’. It is worth noting that personal budgets in social care were introduced after the limitations of attempts to introduce person centred care without personal budget control became apparent. People with long term support needs had creative and personalised care plans, but services were not changing to meet these. The plans were not affecting how money was being spent, leading to disillusionment with the rhetoric of person centred care.

Personal budgets are less established in the health service than in social care. Since October 2014, those adults receiving NHS Continuing Care (and children in receipt of continuing care) have been eligible for a personal budget; since April 2015, CCGs have had the freedom to offer personal budgets.

Personal budgets are an effective form of personalisation. They empower budget holders to make decisions and build on their own personal assets to develop resilience and a culture of self-care or self-management. There is evidence that personal budgets can improve people’s wellbeing, giving them a greater sense of control over their lives and care. Personal budgets should be underpinned by effective care and support planning, as described in the National Voices guide.

Despite the potential benefits, there remain concerns about the impact of personal budgets on the provision of NHS services given scarce resources, and whether the services purchased are always appropriate for the NHS to fund. In this conception, personal budgets allow people to ‘opt out’ of statutory services. The sustainability of such services could be at risk if personal budgets are funded from the same budget and ‘follow’ budget holders. Further, there are concerns that personal budgets extend the provision of healthcare by private providers, as budget holders can choose which services to access, potentially undermining the NHS’s status as a national, comprehensive health service.

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5 Bennett, S (2014) Getting serious about personalisation in the NHS, TLAP, LGA, NHS England, ADASS
7 http://www.nationalvoices.org.uk/what-care-and-support-planning
There have also been concerns expressed that personal budgets are used as a form of cost cutting, not least because the expansion in their use in social care coincided with significant cuts to social care funding by central government. This paper does not seek to address this argument directly.

We know that greater personalisation improves experience of services and outcomes; personal budgets are an effective tool to achieve this. However we share concerns about the level of social care funding (and about NHS funding) which we have set out elsewhere.

This paper seeks to demonstrate that fragmentation, individualisation, and privatisation are not inevitable consequences of the use of personal budgets across health. It sets out why our organisations believe that personal budgets are consistent with the values of the NHS, and can be implemented in a way that in fact strengthens the support accessed via the NHS.

Context and use of terms

Until now we have tended to hear about ‘personal budgets’ in social care; and about moves towards ‘personal health budgets’ in the NHS. But across England local areas, supported by national system leading bodies, are increasingly engaged in joining up care, dissolving the boundaries between siloed services. The government is committed to moving towards more coordinated health and social care.

For the individual, it makes no sense to have two systems of care planning and personal budgets. It must be desirable to create single personal budgets across health and social care where appropriate to the person. This will enable people to have a unified approach to planning their care, treatment and support.

We therefore worked closely with the Department of Health and fellow charities to ensure that the Care Act 2014 legislation and guidance paves the way for unified personalised care and support planning, and unified personal budgets.

Against this background this paper uses the term ‘personal budgets’ to refer to the generic mechanism regardless of the system that funds and organises them.

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1. A policy success story that has become consensus, valued by users

Personalisation is the idea that individuals and their support networks are best placed to be the experts in their own lives and support needs. Personalisation represents a shift from a ‘doing to’ model (in healthcare, the traditional medical model) to a more social model of care. Here, care is holistic and takes into account the needs of the whole person rather than focusing on the disease or disability.

Personal budgets are not the only route to personalisation but have proved to be a highly significant one. As key decision makers in their care, individuals and their families are often more creative, and take more positive risks, than professionals. Putting decision power in the person’s hands creates a more equal, mature relationship, whereby people work in partnership with health and care providers and professionals.

Following increasing pressure from people who use services for more personalised services, a 2005 Green Paper signalled a shift towards personalisation in social care, stating that it should “put people at the centre of assessing their own needs and how those needs can best be met.” Key measures identified included direct payments and personal budgets.

In 2009 the government announced that personal budgets would be piloted in health, arguing this would “improve the quality of patient experience and the effectiveness of care by giving individuals as much control over their healthcare as is appropriate for them.” The pilot results were published in 2012, with the recommendation that the programme be fully rolled out. These showed that when personal budgets are implemented well, they are cost effective in comparison to conventional services and can reduce people’s use of other services.10

A survey of more than 4,000 personal budget holders in health and social care published by Think Local Act Personal shows a positive impact on a range of outcomes, including mental wellbeing, people’s sense of control over important things in life and their perception of being supported with dignity.11

The strength of evidence persuaded the Coalition Government to confirm that, from April 2014, people in receipt of NHS Continuing Care would have the right to a personal budget, extending this to anyone with a long term condition from April 2015.

Introduced initially by a Labour Government, the decision by the Coalition Government (and maintained by the Conservative Government) to expand access to personal budgets demonstrates the political consensus that has emerged around the benefits of personal budgets.

In 2014, Simon Stevens, CEO of NHS England, announced a new programme, ‘Integrated Personalised Commissioning’ (IPC), to develop the more widespread use of personal budgets. The programme particularly targets groups for whom statutory services have historically struggled to provide high quality individual care and support: people with learning disabilities, people with continuing mental health needs, older people living with frailty and children and young people with complex needs.

1111 Waters, J and Hatton, C (2014) Third national personal budget survey: experience of personal budget holders and carers across adult social care and health In control, Lancaster University and TLAP
The IPC programme, for which the first nine sites have been recruited, is now part of the ‘new models of care’ programmes that will implement the NHS Five Year Forward View. The programme is welcomed and supported by voluntary sector organisations including TLAP and National Voices.

2. Personal budgets add value to traditional statutory care, helping people contribute more in a way which can reduce system costs and increase sustainability, and where properly used they can be a new route for people to co-design statutory care services

Personal budgets across health and care can improve people’s outcomes and care experience in a number of ways. They offer support that is social as well as physical, enabling people to manage their condition in a way that allows them to pursue their own goals and interests.

Personal budgets allow more targeted support to meet person-specific needs, so that the way in which a need is met is based not on the condition alone, but on how the person’s wellbeing as a whole can be maintained. This helps move provision from providing reactive, symptom- or disease-specific care to a more comprehensive approach to independence, health and wellbeing.

Personal budgets give people the opportunity to access the type of support that they – in partnership with their professionals – believe will help them meet their personal goals. They should be underpinned by a rigorous process of care and support planning. This is a defined process which helps people identify their own health needs and goals, and how these can best be met, and then secures that support. Care and support planning is the key that unlocks person centred, coordinated care.12

People need more than medical and direct personal care to achieve these goals – they also need to build their confidence and capacity to manage, maintain social and community contact, participate in activities that are important to them, and be supported to adopt and maintain health-producing behaviours such as better diet and exercise.13

Thus access to a personal budget can be seen as allied to the overall agenda of helping people to achieve a better quality of life through supported self-management. Where this is successful, it reduces people’s use of expensive interventions including urgent and emergency care.14 Part of the care and support plan that underpins the budget will be to anticipate and mitigate crisis situations.

This should be cost-effective for the health and care systems. In social care, where people have taken budgets instead of using institutional care solutions, they have proved this cost-effectiveness proposition.

12 National Voices (2014) Care and support planning guide
13 See, for example, NICE Guidance for older people with social care needs and multiple long-term conditions
14 National Voices (2014) Supporting self-management: summarising evidence from systematic reviews
3. Offer personalised and effective support on the same basis as other NHS services: collectively funded through tax revenue, free at the point of use, and (potentially) available to all according to need

There is evidence of strong support for the founding values of the NHS: a comprehensive national health service that is funded through tax and free at the point of use. Analysis of the 2014 British Attitudes Survey shows that 89% of respondents support a health service underpinned by these values.15

We believe that personal budgets are consistent with, and help to realise, these values. In common with other NHS services, personal budgets are a form of taxpayer funding for services, although the direct provider may vary. Budget holders will still access the rest of their healthcare through the NHS, via their GP. It is only the support that is more social in nature, or that cannot be accessed through block contracting, that is covered by personal budgets.

Where the alternative to personal budgets is support through NHS Continuing Care, people are already likely to be accessing care through residential homes or from domiciliary carers working for the private sector. The main difference is therefore the level of choice and control the care recipient has over their provision, rather than a new division between the NHS and the private sector.

Personal budgets have also been used successfully in a number of areas to build very small community enterprises, as a new addition to the voluntary and social enterprise sector, helping the VCS to be part of the market and ensuring that local public service budgets are spent entirely locally.

Care is still publicly funded, underlining the principle that people have a right to the healthcare they need, and that this should be free at the point of use, collectively paid for by society, available according to health need.

4. Can be provided collectively, through a social value approach to commissioning.

Personal budgets (across health and care) can be implemented in a way that encourages and promotes collective provision of care and support through the NHS.

The Social Value Act 2012 says commissioners must consider the impact on social value of the contracts they make. It has been used by local authorities to stimulate and build the local voluntary and community sector assets that contribute to people’s independence, health and wellbeing. So far, it has barely been used by health commissioners.16

Through this and similar approaches, local commissioners can encourage and incentivise the development of user-led, collective and not for profit services.

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Commissioners should work with the voluntary sector to support the development of such services, for example through pump priming grants, or advice to those wishing to develop a service.

The voluntary and social care sectors, along with disability rights groups, have developed a vision of personalisation that balances both choice and control over services, shaping service provision around community action and shared responsibility. Meeting the health and care challenges of an ageing population, with growing numbers of people experiencing disability and multimorbidities, requires real and effective collaboration across these sectors: personal budgets enable people to participate in this collaboration.

5. Service quality: services purchased using personal budgets can stimulate the statutory system to raise quality and be responsive to user preferences.

We fully acknowledge that there is a risk of disruption to existing statutorily funded services as personal budgets are rolled out further. They are likely to prompt a decrease in the block contracting which still dominates the work style of health commissioners.

Indeed, one report argues that implementation of personal budgets requires decommissioning of services in order to be cost effective. However, it also argues that phasing in the changes can mitigate against this risk. This should give existing services the opportunity to adapt and renew.

We believe that this disruptive innovation can be positive for people who use services. Historically, statutory services have been organised around the needs of the service provider, often failing to adapt to the individuals who use them.

NHS funding systems have focused on isolated episodes of activity, such as the number of procedures completed or appointments made, rather than being planned proactively around the person’s needs. The work underway in IPC sites requires local systems to develop patient level data sets showing service usage and costs incurred across the system by people with the most complex needs, including in acute, community, mental health and social care. Understanding these costs at an individual level is a critical prerequisite to making the money work differently - regardless of whether the person takes a personal budget.

Separating commissioning from provision was in part justified by the notion that commissioners would act as a proxy for people who use services to redesign services. Although there are increasing numbers of small scale innovations in this respect, there is so far little evidence that commissioners can enact rapid change towards personalisation at any sort of scale. Commissioning remains dominated by the annual churn of the larger block contracts that use up most of the budgets.

Greater control for people who use services, supported by a process of care and support planning is therefore seen as more likely to drive change in the way services are designed so they become more

18 Think Local, Act Personal (2013) A problem shared: making the best use of resources in Adult Social Care TLAP
tailored to individual needs. This in turn is likely to result in greater productivity and efficiencies across the system.

The feedback which users of personal budgets can provide both quantitatively – in the ‘micro’ data on how they exercise their choice and choose their provision – and qualitatively, in registering their opinions on existing services and how they could be improved, should be seen as crucial information for wider commissioning choices, and for the redesign and improvement of services to meet user preferences.

Giving service providers the opportunity and time needed to respond to feedback and suggestions from users where they do choose to opt out of services (and requiring them to do so) can help protect statutory services when personal budgets are introduced.\textsuperscript{20}

In short, this user feedback helps the public sector in its quest for high quality and responsive care. In this way understanding how people use their personal budgets could help commissioners create better tailored and more effective local services.

6. Equity

Personal budgets can promote more equitable access to the support that enables people to live a full and independent life, strengthening rather than undermining the universal nature of the NHS. Without personal budgets, the choices on offer to most people will be an NHS service that may not meet their needs effectively, or nothing. By comparison, people who are better off will be able to purchase more appropriate support through the market.

Counter-intuitively, therefore, the absence of equitable personal budgets may promote opt-outs; whereas personal budgets can contribute to reducing inequality in access to personalised support. In this respect it is an appropriate role for the state to provide funding in this form.

Additionally, in some circumstances personal budgets can actively promote equity and inclusion for people with long term conditions across other spheres of life. If they are used to purchase flexible support that allows people to return to education, sports, or employment, provide people with certain health conditions with access to community services, from which they might otherwise be excluded.

7. Services can be provided through voluntary and user-led sectors, through mutuals, and through pooled budgets, maintaining a collective element in provision as well as funding

Even where personal budget holders choose to use their budget to access support provided outside the NHS, this does not necessarily mean they will opt for private sector provision.

We noted above that commissioners can use social value approaches to ensure that personal budgets build the community assets and support that are increasingly seen as ‘essential’ to a sustainable health and care system.

Personal budgets can also generate new neighbourhood and community relationships. An example would be paying a neighbour for petrol to take the budget holder to regular appointments such as dialysis, rather than using NHS transport, which could cut down dramatically on waiting times for them. These local arrangements help to reinforce community involvement and volunteering.\(^{21}\)

A further stage is to stimulate and develop new user-led services, as an alternative to NHS provision that retains a collective approach. These can offer a real model of co-production, so that rather than encouraging people to opt out of services, they create the conditions needed to give people who use services a more powerful role in shaping the services and support available.

Voluntary sector user-led organisations can be organised in different ways, some of which offer further opportunities for collective provision of services that are designed by and for the people who use them. Mutuals, for example, give face to face workers and people who use the services a stake in, and shared ownership of, the production of health and wellbeing.

In another model, budget holders can pool their budgets to commission services jointly, including through the development of social micro-enterprises, such as those supported by Community Catalysts.\(^{22}\) The creation of peer networks among budget holders can also help identify where people have similar needs for living well and bring them together to pool budgets or create mutual organisations to provide services.

An IPPR report shows that over a quarter of local areas have developed ‘e-marketplaces’ to support the use of personal health budgets, and more have plans to do so. If designed well, these can make it easier for users to set out what they want, and providers to tailor support; they can also enable group commissioning bringing people together on the basis of shared interests.\(^{23}\)

There are a number of actions health commissioners can take to promote more collective and integrated responses to personal budgets:

- Building advocacy and brokerage into all personal budget development;
- Implementing care and support planning within health services, as described by the National Voices’ guide.\(^{24}\)
- Creating a new model of commissioning in which citizens and communities are involved as well as clinicians and managers;
- Working with councils to include all personal budget holders and health providers in the local marketplaces created for social care personal budget holders, with promotion of collective purchasing;
- Identifying and commissioning new models of provision which have the most potential to deliver wellbeing and resilience outcomes.\(^{25}\)

\(^{21}\) [http://campaigntoendloneliness.org/toolkit/](http://campaigntoendloneliness.org/toolkit/)

\(^{22}\) [Community Catalysts](http://www.communitycatalysts.org/) is a community interest company and social enterprise that nurtures micro community enterprises and groups that offer people support and real choice over their care.


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Conclusions

Personal budgets should be embraced as an important tool for realising the core values of the NHS – providing comprehensive care that is free at the point of use, and is funded by taxpayers.

We recognise that introducing personal budgets across health and care carries some risks to existing collective provision. However, we have outlined ways in which those risks can be mitigated and collective and equitable aspects of personal budget holding can be maximised.

In this sense, personal budgets are a necessary but not sufficient driver for culture change towards person centred care: they must be accompanied by effective state and voluntary sector action to move towards collaborative models of care and to develop locally-based state and VCS providers.

This includes using feedback from people using the services to strengthen, improve and redesign existing provision to achieve higher quality and greater responsiveness. Now that the social care success story has become policy consensus, any government should be able to adopt these goals.

Personal budgets should therefore be seen not as a potential opt-out but as a welcome advance towards more ‘people powered’ services.

This is in the context of the gathering momentum of wider system change towards person centred coordinated care; asset and capabilities approaches; community development; coproduction and shared responsibility.

Personal budgets offer an opportunity to show that the government of the day and health and care system leaders have faith in people to work together.
Appendix: Benefits of personal budgets

There is growing evidence that personal budgets in health and care can improve people’s experiences of services and support, and their wellbeing.

The final evaluation of the Department of Health’s personal health budget pilot looked at the effects of personal budgets in a number of arenas. This longitudinal study found:

- Personal budgets were associated with significant improvement in the care-related quality of life and psychological wellbeing of recipients;
- They did not have an effect on people’s health status (clinical measures of HbA1C and lung function) over a 12 month follow up period;
- High value personal budgets (over £1000) had more positive outcomes than low value budgets;
- Personal budgets had particularly positive effects on outcomes for those with COPD;
- Costs associated with inpatient care were lower, but direct costs of wellbeing and other health services were higher than for the control group. In other areas there was no cost difference;
- Cost effectiveness was greater for higher value budgets and where holders had greater choice and control over their services.

The evaluation demonstrated that the design of the personal budget process has a significant effect on outcomes, with better outcomes where:

- Budget holders were explicitly informed about the budget amount
- They provided a degree of flexibility as to what services can be purchased
- Budgets provided more choice in how the budget can be managed

The 2015 Personal Outcomes Evaluation Tool Survey of 307 personal health budget holders found that they felt that personal budgets had a positive impact on their:

- Quality of life (85 per cent)
- Independence (81 per cent)
- Self-esteem (76 per cent)
- Control over life (74 per cent)
- Friendships (68 per cent)
- Physical health (63 per cent)
- Mental health (69 per cent)

Tailored support services can be particularly important for conditions that are less common, and for minority groups including young people, BAME groups and those who do not have English as a first language. Tailoring could mean, for instance, training care workers to deliver insulin or other medical treatments to help people attend college, an iPad instead of bulkier communication aids to help

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27 In Control, Lancaster University and TLAP (2015) Personal Health Budget Holders and Family Carers: the POET Surveys 2015
someone stay at work, training care workers to specialise in particular conditions, or hiring care workers with language skills or an understanding of particular cultures. It would be difficult to achieve this degree of personalisation within a service commissioned for a whole population.

Personal budgets can help people to maintain their health in a way that makes sense to them, helping them to avoid their health deteriorating, or having to go into hospital for more acute care. Those with fluctuating conditions, for example, can plan ahead to ensure that when their condition deteriorates, they have a plan in place in advance for the care they need, which can help people avoid long stays in hospital while this is being arranged.

Personal budgets can also help to reduce inequalities by enabling people to purchase non-traditional services they would not otherwise be able to afford. For example, how well an individual manages long term conditions is not only dependent on following medical advice, but on how well they eat, exercise and address any underlying mental health problems. Interventions to address healthy behaviours have historically not been provided for within the NHS and thus there is a lack of equity to these resources.

As people are supported to identify their own personal goals through care and support planning, commissioners will be alerted to an increase in the demand for these types of interventions which in turn will stimulate the local markets to respond to the needs of the local population.

Personal budgets can empower people who use services to become stronger advocates for their own needs. Knowing the cost and having the responsibility of purchasing support directly can help people feel they have a right to complain about poor service from support agencies, and their power as a direct commissioner can make agencies more responsive to their concerns. This could help improve quality.
**National Voices** is a coalition of over 140 health and social care charities in England. We work for a strong patient and citizen voice and services built around people. We stand up for voluntary organisations and their vital work for people’s health and care.

[www.nationalvoices.org.uk](http://www.nationalvoices.org.uk)

[@NVTweeting](https://twitter.com/NVTweeting)

**Shared Lives Plus** is the UK network for family-based and small-scale ways of supporting adults. Our members are Shared Lives carers and workers, Homeshare programmes and micro-enterprises. Shared Lives used to be known as Adult Placement.


[@SharedLivesPlus](https://twitter.com/SharedLivesPlus)

**In Control** is a national charity working for an inclusive society where everyone has the support they need to live a good life and make a valued contribution

[http://www.in-control.org.uk/about-us.aspx](http://www.in-control.org.uk/about-us.aspx)

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**Think Local Act Personal** is a national partnership of more than 50 organisations committed to transforming health and care through personalisation and community-based support.


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