

# The Boundaries of Budgets: why should individuals make spending choices about their health and social care?

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## Summary

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This analysis looks at four key arguments that have been made to justify the use of individual budgets. First, individualised budgets improve outcomes for individuals; second, budgets extend choice and control to citizens, which they should have as a matter of right; third, budget-holding has an important educative function for individuals, enabling them to share in a common citizenship; fourth, budgets correct system-level failings in public services.

It argues that individual budgets do have proven value in meeting claims one and two (improving outcomes and upholding rights), but not in meeting claims three and four (widening financial literacy and triggering system-level improvements).

The analysis focuses primarily on personal budgets in social care since this is the sector in which the evidence base is most mature, but it also considers the existing or likely impacts of personal health budgets where possible.

**Claim 1:** *Personal budgets lead to better individual outcomes?* Whilst there is evidence about the positive impact of individualised budgets on outcomes, the types of outcomes tend to be more about control and well-being rather than traditionally understood health benefits.

**Claim 2:** *A matter of right?* Whilst personal budgets enhance the rights of patients and service users in taking control of their care, the exercise of this right depends heavily on equity of access. Patterns in the take-up rate of direct payments indicate that marginalized groups are continuing to be excluded.

**Claim 3:** *Financial Inclusion?* There is very little support within the evidence for the claim that the use of individualised budgets – across a range of sectors – improves financial inclusion and financial literacy. Rather, the evidence highlights the dangers of inequity between those with financial and social resources to supplement their use of budgets and those without.

**Claim 4:** *Fixing the system?* The experience of self-funders in social care suggests that the use of personal budgets will not address the overall failures of a poorly regulated market in social care services which is delivering suboptimal outcomes.

## *Introduction*

1. The post-war welfare state set up a division between cash transfers and state services, based on the assumption that citizens were the best purchasers of some services (e.g. food, clothing) and that the state could purchase others more effectively (e.g. health and social care). However a number of interrelated developments have increased the scope of services which are allocated in a cash form or via a notional budget. Within the social care sector initiatives to transfer resources to disabled people as direct payments began in the 1980s, and were given legal endorsement in the 1996 Community Care (Direct Payments) Act. Local authorities are currently required to move at least 70 per cent of eligible users onto a personal budget, which may be in the form of a direct payment or a managed budget (with funds remaining with the local authority), or a combination of the two. To be eligible, people must satisfy two criteria set by local authorities: they must be sufficiently frail or disabled to pass the need threshold for receiving services, and they must also satisfy a means-test to indicate that they are too poor to pay for their own care.

2. Personal budgets are part of the broader personalisation agenda within social care which aims to increase choice and control. The agenda also includes steps to improve prevention (such as spending money on early intervention support to keep people out of hospital), to enhance social capital (by making it easier for people to take part in community activities) and to improve access to universal services such as public transport, libraries and leisure centres.<sup>1</sup> Within social care, personal budgets are now a mainstream approach, with over 50 per cent of older and disabled people holding such a budget.<sup>2</sup> The majority of these are held by the local authority as a managed personal budget rather than a direct payment to the user. However, even with these managed personal budgets the principle remains that people should be told the amount that is in their budget and make choices about how it should be spent.

3. This agenda is not confined to social care. Despite significant differences between social care and health systems (for example there is no mean-testing for core NHS services), the perceived success of social care budgets has led to the piloting of budgets within the NHS. These personal health budgets have been trialled in the NHS for people with a range of conditions such as diabetes and asthma and for users of mental health services<sup>3</sup>. These budgets are now being rolled out nationally for people on continuing healthcare funding, and localities are being encouraged to offer them to people with long-term conditions. Patients can opt to manage the money themselves, following new legislation on direct payments in health. Alternatively, they can work with health professionals or a third party to identify how to allocate a notional or managed budget. Budgets are also being introduced for the parents of

children with disabilities and special educational needs, and are being proposed for a range of sectors such as adoption services and rough sleepers. Individualised budgets are also part of the Department of Work and Pensions' (DWP) Right to Control initiative to get disabled people into work. <sup>4</sup>Plans for a range of benefits, including housing benefit, to be combined into a monthly 'universal credit' paid directly to tenants could arguably be seen as part of the same trend <sup>5</sup>. This builds on the model of the Local Housing Allowance (LHA) through which eligible tenants in private rented accommodation receive their housing benefit directly, rather than the government paying it to the landlord. If tenants are able to secure a cheaper rent they can keep the additional money, or they can top up the rent to access more expensive accommodation<sup>6</sup>.

4. The increasing disaggregation of budgets down to the individual level in the form of cash or a notional allocation has generated intense debate in the various sectors in which it has occurred. The most extensive debates to date have been within social care where the policy is furthest advanced and where a set of recurring themes dominate the academic and practitioner literatures: do personal budgets turn care recipients into consumers or do they offer the means for people to become active citizens? Do personalised care services empower the budget holder or do they off-load responsibilities from the state to the individual? Can the rights of older and disabled budget holders be respected at the same time as the rights of carers and care workers? Such debates tend to keep being repeated because the terminology (citizen, consumer, etc) is unstable, experiences are heterogeneous and hard to measure, and policy and funding contexts are constantly shifting.

5. To contribute to these debates without repeating them, this article interrogates the various rationales that have been put forward to justify the devolving of budgets down to the individual. Whilst some observers of personal budgets have seen them as yet another outlier for neo-liberal state retrenchment, the discussion here will focus on the positive claims of individual and social benefit which have been articulated by personalisation advocates. Four claims are examined here: first, individualised budgets improve outcomes for individuals; second, budgets extend choice and control to citizens, which they should have as a matter of right; third, budget-holding has an important educative function for individuals, enabling them to share in a common citizenship; fourth, budgets correct system-level failings in public services. These are not the only claims that are made about personal budgets. There are others, particularly their capacity to save money or to build social capital. However it can be argued that both of these are means to achieve the other claims set out above. The financial case for personal budgets is highly contested, with the Department of Health expecting them to be cost-neutral but many local authorities seeing them as a key part of reducing social care costs (for a discussion of this see Beresford, 2011).<sup>7</sup>

6. The discussion below argues that individual budgets do have proven value in meeting claims one and two (improving outcomes and upholding rights), but not in meeting claims three and four (widening financial literacy and triggering system-level improvements). The discussion focuses primarily on personal budgets in social care since this is the sector in which the evidence base is most mature, but also considers the existing or likely impacts of personal health budgets where possible.

*Claim 1: Personal budgets lead to better individual outcomes?*

7. There is a growing body of evaluative data from social care indicating that people derive benefits from holding a personal budget to make care choices. The Individual Budgets (IB) evaluation (IBSEN) funded by the Department of Health found: 'People receiving an IB were significantly more likely to report feeling in control of their daily lives, welcoming the support obtained and how it was delivered, compared to those receiving conventional social care services'.<sup>8</sup> These findings were strongest for people using mental health services and weakest for older people.<sup>9</sup> The National Personal Budget survey conducted by Think Local, Act Personal (TLAP), Lancaster University and the social innovation network *In Control* found that 'substantial majorities of people reported personal budgets having a positive impact'.<sup>10</sup> People receiving their social care budget as a direct payment have more transformative outcomes than people whose budgets are managed on their behalf by the local authority or a third party. According to the National Personal Budget survey: 'Whilst all personal budget holders reported positive outcomes, those managing the budget themselves as a direct payment reported significantly more positive outcomes than people receiving council managed budgets'.<sup>11</sup>

8. Within the health sector, the personal health budget evaluation found that such budgets produced 'valued well-being benefits'.<sup>12</sup> These benefits came not from improved health outcomes (where the evaluation did not find statistically significant improvements) but from improvements in care-related quality of life and psychological well-being, which the researchers refer to as 'higher order' aspects.<sup>13</sup> Care-related quality of life includes people's achievement of everyday activities such as dressing and feeding, as well as feeling safe and being occupied. Improvements on psychological well-being measures includes levels of concentration, self-esteem and ability to sleep.

9. These improvements are distinct from the sorts of health outcome measures which the study also looked for, such as reduced hospital admissions or lessening of pain. However, they are nonetheless important. The psychological benefits of giving people more control are well known. As Glasby and Littlechild put it, 'There is a large literature in the field of psychology to suggest that control is essential to wellbeing

and an important element in shaping people's lives and their susceptibility to stress...For many direct payments recipients, enhanced choice and control increased their self-confidence, morale and emotional and psychological health in a range of areas'<sup>14</sup>.

10. The mechanism through which personal budgets improve well-being and other outcomes is often assumed to be the purchasing power that comes with financial control.<sup>15</sup> A member of *In Control* told the author in an interview, 'Until I've got hold of the money, or at least I'm directing the way that that money's spent, that provider is never going to listen to me. It's the power of the pound, the power of having the money is the bit that makes the difference'.<sup>16</sup> However, a feature of the evaluations of budget-holding across social care, the NHS and rough sleepers is the value that people place on the support planning process in which they sit down with a professional or other support worker and talk about their needs, preferences and capabilities. As a participant in the rough sleepers pilot put it, 'I've got to be honest here, it wasn't just the individual budget, it was the fact there was [co-ordinator] there as well ... We was meeting [regularly] to discuss it, and I'd actually gone from the stage of wanting nothing to do with these people, to actually looking forward to seeing them'.<sup>17</sup> Similar findings – about the value of building relationships with care providers – have emerged from the social care and health budget evaluations, highlighting that the one to one support that accompanies a budget is at least as important to improving wellbeing as the money itself.

11. Overall, then, whilst there is evidence about the positive impact of individualised budgets on outcomes, the types of outcomes tend to be more about control and well-being rather than traditionally understood health benefits. Building relationships and taking time to understand someone's support needs play a key role in achieving these outcomes.

### *Claim 2: A matter of right?*

12. A second rationale for personal budgets is a rights-based argument, namely that such budgets are designed to allow people to make the sorts of choices about their health and social care which are theirs by right to make. The local authority block contracts that preceded personal budgets often gave people very little choice about how and by whom their care was provided. Within social care, those people who are now making use of personal budgets are choosing the times they get up and go to bed, the timing and content of meals, how they receive personal care, as well as how they spend their days, issues on which they can reasonably expect to have autonomy. The personalisation reforms are premised on an assumption that people are 'experts on their own lives', and social workers are expected to work within that paradigm.

13. Within the health sector, the boundaries between clinical knowledge and patient knowledge have not shifted so far, but the rise of expert patient programmes highlights a growing confidence that there are a range of health conditions on which patients have a normative claim to expertise and autonomy.

14. This is of course not to claim that making spending choices about health and social care is not a complex and uncertain process in which people need support. The National Personal Budget survey found, 'The single most commonly commented upon issue in the survey was a lack of clarity, often regarding how money could or couldn't be used, but also concerning other aspects of personal budgets as well'.<sup>18</sup> Inequalities in the capacity of citizens to navigate complex care systems has been a concern raised by many people, particularly in the context of personal budgets.<sup>19</sup> Relatively low take-up of direct payments by older people, people with mental health problems, and people from ethnic minorities are indicative of the sorts of issues which are likely to be faced in making these rights meaningful for the full range of people using social care services.<sup>20</sup>

15. Advocates of personalisation argue that the care systems that predated personal budgets were themselves characterised by complexity, lack of transparency and inequity. Hatton points out that these issues have not been created by personal budgets and should not be a reason to reject them: 'Plenty of evidence exists that social care services tend to be directed towards those with the skills, tenacity and resources to negotiate byzantine systems. However, this is not a specific issue concerning direct payments - it is a pervasive one found throughout social care'.<sup>21</sup> The aim of personalisation advocates was to simplify the complex process of social care assessment and allocation of services into a transparent series of steps; an ongoing frustration for reformers has been the tendency of local authorities to overly bureaucratise the allocation and monitoring of budgets.<sup>22</sup>

16. Thus whilst personal budgets enhance the rights of patients and service users in taking control of their care, the exercise of this right depends heavily on equity of access. Inequities and barriers to access have not been created by personal budgets, but patterns in the take-up rate of direct payments indicate that marginalized groups are continuing to be excluded.

### *Claim 3: Financial Inclusion?*

17. A feature of welfare reform over several decades has been the encouragement of individual financial literacy and responsibility with the avowed aim of incorporating people into a common citizenship.<sup>23</sup> The

previous government's Child Trust Fund was an exemplar of this approach.

18. Efforts to give citizens more direct control over financial resources through personal budgets could be seen as an extension of this educative function. The rationale for the Local Housing Allowance (LHA), for example, is set out by government as follows: 'By paying LHA direct to the customer it ensures they take on the personal responsibility of paying the rent to the landlord and helps develop the budgeting skills unemployed people will need when they move into the workplace. It also plays a part in the wider cross Government strategy of greater "financial inclusion."' <sup>24</sup>

Personal budgets and health budgets can be similarly linked to the enhancement of financial literacy and the promotion of financial inclusion. The payments give people choices that may previously have been denied to them and incentivise careful budgeting since people can benefit directly from more frugal use of resources. Writing in a social care setting, Spandler notes that 'Powerful personal incentives exist for recipients to use their money wisely, efficiently and prudently because their survival and independence depend upon it'. <sup>25</sup> As well as being more frugal, the service user may take on some of the hidden costs of the system: 'because the user often acts as an employer and budget holder, he/she soaks up much of the administrative and management costs. This may mean that recipients can get greater levels of social care at no greater cost.' <sup>26</sup>

19. Welfare reforms which purport to build civic inclusion and financial literacy through individualised financial labour and increased exposure to risk have drawn widespread criticism. <sup>27</sup> Writing in a care context, Scourfield notes: 'Direct payments fit comfortably with the project to transform the culture of the public, private and informal care sectors around principles of innovation, risk taking and enterprise.' <sup>28</sup> This can perhaps be understood as a distortion of the citizen's income arguments put forward by the left, in which financial inclusion is not promoted as part of an equal citizenship but on condition of compliance with activation policies around work and the family. <sup>29</sup>

20. There is very little support within the evidence for the claim that the use of individualised budgets – across a range of sectors – improves financial inclusion and financial literacy. The notion that citizenship is enhanced by getting welfare recipients to frugally seek out resources is a troubling one. Like the other claims, it highlights the dangers of inequity between those with financial and social resources to supplement their use of budgets and those without.

#### *Claim 4: Fixing the system?*

21. There is great optimism from personalisation advocates about the potential for personal budgets to fix the problems which are evident in the existing system of social care support. The ambition of organisations like *In Control* (the lead campaigning organization for the extension of personal budgets) has been very much system-wide, recognising the limitations of the social care market. Personal budgets are seen as a way in which individuals can tackle some of the many limitations of existing social care provision, whether it is risk-averse professionals limiting people's choices, large block contracts proving too restrictive to meet people's support needs or private companies providing a very poor standard of care.<sup>30</sup> The vulnerabilities of a care market funded by venture capital were starkly demonstrated with the collapse of the Southern Cross group, a large provider of residential care homes.

22. These structural problems have a knock on effect on the social care workforce, which is well known to be low paid, with poor training standards and insecure working conditions.<sup>31</sup> A report into social care by the Equality and Human Rights Commission found 'serious, systemic threats to the basic human rights of older people who are getting home care services.'<sup>32</sup> This conclusion echoed the findings of the *Time to Care* report into the home care sector, published by the Commission for Social Care Inspection (CSCI) in 2006, which found: 'the sector itself is a fragile one, that is struggling already to provide services of sufficiently high quality for those who need them now...A gap appears to be developing between what people themselves want and need, and what is on offer from statutory services'<sup>33</sup>.

23. The market power of individual budget holders is an inadequate force to challenge such systemic failings. There may be some improvements at the margins. Workforce changes may be brought about as more people shift to employing a personal assistant, rather than using social care agencies. Personal assistants have been found to have higher job satisfaction than agency workers, but they again can be a poorly paid and isolated workforce with little access to training.<sup>34</sup> Innovative third sector organisations providing quality care services are expected to benefit from the market stimulus of lots of individual commissioners but may simply be unable to operate on the basis of such an insecure funding stream.<sup>35</sup>

24. To understand why individualised budgets are unlikely to challenge system-level inadequacies, it is useful to study the experience of self-funders in the care system, i.e. those who do not meet local authority criteria on level of need or lack of means. Unlike 'early adopters' of personal budgets and direct payments, who may have characteristics which make them particularly well suited to managing care spending (and

therefore from whom it may be difficult to generalise about mainstream impacts), self-funders includes all those who are ineligible for local authority funding, which may say little about their support networks or financial acumen. They are large in number (forty per cent of older people are estimated to make some financial contribution to their care costs and many have purchased care over a long period making them a useful comparator group.<sup>36</sup> Self-funders have not tended to be well-studied, and have rarely been evoked in personalisation debates to inform understandings of how financial control intersects with care, perhaps because the drive for direct payments has come from younger disabled people where self-funding is less prevalent.<sup>37</sup>

25. A report on self-funders commissioned by the Putting People First Consortium, noted, 'For some people there was a profound sense of "powerlessness" and lack of control over their own financial resources, coupled with some real fear over what would become of them if their savings ran dry...It is clear that having sufficient resources to be a self-funder does not automatically give people greater control over their situation, and meaningful choices are often lacking.'<sup>38</sup> It is certainly the case that the existence of a large bloc of self-funders has not led to the emergence of affordable, good quality care for older people, as the endemic problems in the quality of home care services attests.<sup>39</sup> A poorly regulated market intersects with the intimate nature of social care (and its complex intersection with vulnerability, autonomy and dependence) to make individual market efficacy relatively weak.<sup>40</sup>

26. The need for a system wide fix is very apparent in social care, but much less so in health (despite what the current government's NHS reform agenda would suggest). The problem which personal health budgets seem designed to address is the growing numbers of people with chronic health conditions, and the value (normative and financial) of recruiting them as expert patients. The funding landscape in health is also so different to social care that it is hard to read across, given that the NHS is a universal service whereas social care is means tested.

27. There are currently no NHS analogues to social care self-funders, although with the likelihood of an increasingly commercial basis for many NHS services, there is an increased possibility of top up payments being introduced to supplement a core set of NHS services, exposing health budget holders to the same market vulnerabilities that are very familiar from social care. The personal health budget evaluation noted, 'Policy makers should anticipate that the use of personal health budgets is likely to result in a higher level of expenditure going to "non-conventional" (i.e. non-NHS) providers. Further research is required to better understand the scale of these changes'.<sup>41</sup> Thus the experience of self-funders in social care suggests that the use of personal budgets will not address the overall

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failures of a poorly regulated market in social care services which is delivering suboptimal outcomes.

## Conclusion

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28. Personal budgets have been a very positive intervention for some people using social care services, particularly those that have been able to take the money as a direct payment. There have also been benefits for people holding personal health budgets. However, the tentative nature of these findings should be noted: they have tended to be observed among groups of 'early adopters', the benefits have been more around wellbeing than health outcomes, and they may be in part attributable to the time spent on support planning than on the spending choices made. Nonetheless there is sufficient data to see that there are some positive individual outcomes for people who choose to make care and health spending choices themselves.

29. There is also a rights-based rationale for including people more directly in choices about health and social care. Making choices via a budget is a complex process and the ability to do so is not equally shared, but there are intrinsic and instrumental reasons for believing that individuals – with families and communities – ought to play a key role in making those choices where they want to do so. The difficulties that people face in making effective decisions about care should be a reminder of the importance of ensuring that people are well-supported, particularly through peer support and advocacy networks which can draw on shared experience. It is also important to reaffirm that people's care choices and eligibility criteria do not have to be located in ever-more complex systems which even experienced observers find difficult to fathom.

30. The claim that controlling money is a way of teaching citizens valuable financial skills is harder to sustain, having its roots in a view of 'active welfare' that is premised on forcing people to take on responsibilities. The risks and complexities of being a budget-holder will not be welcomed by all and making them compulsory is anathema to the principles that animated the independent living campaigns for direct payments.

31. The claim that budgets themselves will fix systemic problems in care provision is also unconvincing. There are distinctive attributes of care that act as important intervening variables in understanding how market changes play out. The self-funder experience highlights the complex interplay of market and social norms in a sector in which system-level marketisation is well-established. A highly commodified sector has delivered a poor quality of care to those with and without their own purchasing power, largely because neither local authorities nor individuals have sufficient resources to meet the real costs of care or to

demand effective accountability from providers. National action on the long-term funding of adult social care is required, with the government's recent commitment to introducing a cap being a welcome start. However, the King's Fund have rightly warned that this is only part of what will be necessary to meet future social care costs.<sup>42</sup>

32. Rather than seeing personal budgets as a way of giving people leverage to fix the problems of the social care market, they can be viewed as an effective tool to stimulate change for some service users, although probably at the fringes rather than in the mainstream. Mainstream benefits may be best harnessed through focusing on the relational aspects of support planning, drawing on the evaluation findings about the value people derive from talking at length to a professional or support planner about their capabilities and aspirations. However the implementation of individualised budgets in times when austerity so dominates the welfare terrain makes it hard to imagine that these relational benefits can be sustained beyond the scale of (usually well-funded) pilots. There is a danger that the experience of the NHS London choice pilots for secondary care will be repeated, when choice advisors (found to be a key aspect in helping people make choices and navigate complexity) were not a funded part of the policy when it was rolled out nationally.<sup>43</sup> If this is also the experience of the national roll out of personal health budgets then the benefits found by the evaluation team may soon dissipate.

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