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Are personal budgets necessarily empowering for service users? If not, what's it all about?

Professor Peter Beresford

Brunel University and Chair, Shaping Our Lives

Abstract
A growing body of evidence highlights problems with moves to personal budgets and 'personalisation'. At the heart of these problems are the continuing low priority and inadequate funding of social care - issues that look set to get worse. This article seeks to remind us of the underpinning values of person-centred support and the urgent need for a radical re-prioritisation of social care.

Keywords: Personal budgets, direct payments, service users, disabled people

A 2011 text identifies five key themes in the narrative of personal budgets and personalisation. One of these is that 'personalisation saves money':

> *Improved outcomes need not come at a higher cost, since personalisation is likely to save money.* (Needham, 2011, p.50)

A number of studies and authors associated in one way or another with In Control and Simon Duffy, the high profile early advocates of individual and personal budgets, made this claim (Glasby & Littlechild, 2009, p.125; Duffy, 2010). Perhaps the most extreme of these was Charles Leadbeater of Demos. In 2008, he suggested that savings 'could be as high as 45%' (Leadbeater, 2008; Leadbeater *et al.*, 2008).

Yet this claim has never been convincingly evidenced by independent studies and what research has addressed this point has generally come to the conclusion that such developments are at best 'cost neutral' (Glendinning *et al.*, 2008). As Catherine Needham says: 'the "it works" and "it saves money" rationales are the key hard indicators that justify personalisation' (Needham, 2011, p.51). Put another way, politicians and policymakers have been unable to resist the siren cry of a policy that it was promised would both save them money and improve services and support. The likelihood, especially in social care, a notoriously under-funded area of policy constantly in search of cost-saving changes, of such promises being true, seems minimal. Social care's history is littered with previous examples of such over-claimed and inadequately evidenced innovations, from 'patch' social services in the 1980s through to care management in the 1990s. All of these have subsequently been seen to fail.

However 'better for less' was the story that attracted politicians to individual and personal budgets. This is in significant contrast to the direct payments from which they were derived, which were developed only hesitantly and patchily at both central and local state levels. The narrative of individual/personal budgets was then sold powerfully through stories from some service users of new flexibility and opportunities in their lives, far better than reliance on traditional services. Better also than existing over-policed and over-managed direct payment schemes (http://www.guardian.co.uk /society/2008/jul/02/longtermcare.socialcare2 accessed 7 September 2011). We then moved from a few pilot projects to a massive cash injection from central government to 'transform' social care and targets of moving service users to personal budgets that ranged from one third to all. The latter is the current goal set by government for 2013 (SCIE, 2010).

There were, nonetheless, dissenting voices; people who said this development would not necessarily be cheaper; that there was much more to it than was being suggested. Such voices, such cautions, however, were not welcomed. I know that it is the case, because I was one of them and I watched others marginalised who expressed similar concerns, excluded from conference platforms, key forums and public and political discussions (Beresford 2007, 2008).

This was prior to the emergence of a strong body of evidence, when even before government had the results of its own research, it was committing itself to making massive policy change in favour of personal budgets. Then when it gained evidence from the IBSEN study, this highlighted that it was difficult to unify different funding streams – as had been promised of the individual budgets that had then been most talked about and that there seemed to be major problems accessing all groups to personal budgets, notably the largest group, older people (Glendinning *et al.*, 2008).

Now more evidence is available about personal budgets. There has, for example, been the recent Community Care Unison survey. Headlines from this include that:

- 83% of those surveyed said cuts to adult care budgets in their areas would impede the operation of personal budgets;
- almost half (48%) thought personal budgets were not of sufficient value to help users meet their needs;
- 37% disagreed that the resource allocation system in their area effectively allocated money to people in line with their needs - 47% agreed;
- 33% said resources had been the greatest barrier in making progress with implementing personalisation;
- 57% saying that users did not have a genuine choice of services from the social care market, and evidence that personal budgets were not changing the services that people received;
- 44% of respondents said people were generally buying the same kinds of support under personal budgets as under traditionally commissioned packages of care. Just 3% said most people in their areas were buying different kinds of support with personal budgets than before.

Now, only a minority of social workers believe that personal budgets will benefit services users in the medium to long-term (http://www.communitycare.co.uk/Articles/2011/05/25/116868/social-workers-losing-faith-in-personalisation.htm, accessed 25 August 2011).

Two major studies in mid 2011, an Association of Directors of Adult Social Care survey of progress on personalisation and the Personal Budgets Outcome Evaluation Tool (POET) survey, both highlighted problems and a lack of progress. The national personal budget survey carried out in 2011 by In Control, the organisation most closely associated with the advancement of personal budgets, reports positive results, but also according to David Brindle of the Guardian:

> *… adds the critical rider that personal budgets work well for everyone when they get full support to maximise the advantages. Short of that, the idea can be tarnished.* (Brindle, 2011)

And he cites Rob Greenland of Social Business Brokers who says:

> *People are starting to publicly acknowledge that we are struggling to make personal budgets work.*

Brindle also cites the Association of Directors of Adult Social Services as admitting:

> *… that only one in three budgets is given*

> *in the form of a direct payment. Most people are told how much they are entitled to, but never get to handle the money. "Nearly all the increase has been in 'managed' personal budgets, with no significant increase in direct payment numbers in the last year", the association says.* (Brindle, 2011)

These are exactly the points that critics concerned with the rights and needs of service users and carers have been raising since government first determinedly nailed its flag to the massive roll out of personal budgets.

To sum up, putting together accounts repeatedly reported back from the ground and what independent evidence we have, the picture now is of:

- frequently heavily bureaucratic resource allocation systems;
- reducing eligibility in a time of severe cuts;
- reduced (personal) budgets;
- cash sums top-sliced for administration;
- service users without adequate support to manage schemes;
- some local authorities simply treating the move to personal budgets as a numbers game, rebadging the same old service arrangements in cash terms as if it meant anything different;
- a postcode lottery of how transformation actually implemented, with some localities making real attempts to improve and change and others acting as if they hoped if they did nothing it would all eventually go away.

While this is the context for developments around personal budgets and personalisation, it is far from the whole story.

To address the questions posed in the title of this paper, we have to look at two really big issues involved:

1. The shift from the direct payments developed by the disabled people's movement to the individual and personal budgets we have come to talk about.
2. What personalisation really means?

Individual budgets (IBs) and personal budgets (PBs) were advanced earlier in the noughties as a brave *new* idea. But the reality is they are precisely derived from the direct payments created and developed by the disabled people's movement almost a generation earlier. Direct payments are a groundbreaking development rooted in pioneering philosophy, values and theory. They grow out of the social model of disability and the independent living movement. Their essential aim was to put disabled people, and then other service users, in control of their support as part of a broader independent living approach, which would also work for full and equal inclusion, access and participation in mainstream life and services to enable them to live on as equal terms as non-disabled people (non-service users).

Thus from the start they were rooted in a set of clear values and yardsticks:

- the service user would be in control of their support;
- they would have the support they needed to be able to manage a direct payments system – probably provided through a local user led or disabled people's organisation;
- the amount of money provided would match the needs they had in order to secure their equal human and civil rights (Campbell & Oliver, 1996; Oliver & Barnes, 1998).

Direct payments were slow to develop, especially in some areas. There was little determined pressure from the centre for them to do so. They were frequently over-policed and over-controlled and not necessarily even understood by the local authorities made responsible for implementing them –

although disabled people's organisations always had reservations about them being in charge.

But the new impetus for PBs and IBs was very different. It was divorced from all these key criteria established by disabled people:

- they would not necessarily truly be in control;
- they certainly would not necessarily be ensured the support to run them;
- the amount of money provided was not linked with any criteria of independent living, but rather simply a reallocation of existing generally inadequate funding within arbitrary and unhelpful eligibility criteria and means testing.

Because of this it is not surprising if they are now being associated with the problems we have heard about. It is also no wonder if they are heavily ambiguous in operation. Understandably, many committed practitioners have increasing reservations about them and they are being called into question both by practitioners and service users' organisations.

From a means to empowerment, we have moved to what is essentially an under-funded voucher system. From a replacement for a traditional and inadequate set of services, we have moved to an exchange relationship, which casts the service user as a consumer, not a citizen with rights – to a model that is market based and market driven rather than liberatory in intent. Of course personal budgets may still benefit some service users. This would not be difficult, unfortunately, given the poor quality of much traditional social care provision. But that is not what we were promised. We were promised something much better for *all* and that is not happening. There is also no evidence it ever will, when the existing approach chimes so well with the cutting, privatising, individualising approach to social care and indeed other public services, that has in recent years to different degrees gained major cross-party political support.

This leads to the second big issue under consideration here; as to what the term personalisation really means. Some time ago government began to encourage us not to see personal budgets and personalisation as synonymous, even though that is how they were initially presented both by government and the initiative's supporters. Personal budgets, we were now told, were meant as a delivery system. The *goals* were choice and control. We are now learning from the evidence that personal budgets can fail as a means to deliver just like any other. So it is perhaps helpful to get back to the goals. It will be beneficial to stay for a moment with the government's understanding of personalisation as meaning increasing choice and control, by whatever means (HM Government, 2007; SCIE, 2010).

To make more sense of personalisation and its meanings, focus can be turned to the large four-year research and development project supported by the Joseph Rowntree Foundation in which I have been a partner and whose findings were published in 2011, the Standards We Expect project (Beresford *et al.*, 2011). We didn't use the word 'personalisation' – which we found an inaccessible jargon term and instead we started with the term person-centred support.

The project had three main aims. We wanted to hear what people at the front line of social care saw personalisation or person-centred support as meaning, what barriers were in its way and how these could be overcome. There was considerable consensus among these constituencies about these issues, a lot of common meanings and understandings emerged among service users, carers, face-to-face practitioners and middle managers – the groups whose views we sought and focused on, even though there were some differences of emphasis.

They talk about person-centred support in terms of seeing people as individuals and organising services and support around them, rather than vice versa –'treating people how you would want to be treated' so that 'the power is with the person, not the organisation'.

The barriers in the way of personalisation, or person-centred support, highlighted in the project were many and they interacted to magnify the problems they created. They include:

- the poor terms and conditions of workers which make it impossible to sustain the reliable high quality workers workforce required;
- over-reliance on unpaid carers who lack the support to have real choice themselves, or to ensure it for service users;
- continuing institutionalisation for long term service users both in their own homes and in some residential services;
- organisations that are just not geared up to ensuring choice and control for service users;
- occupational practice that too often still is inadequate and based on a one size fits all approach;
- service users lacking adequate access to mainstream life, services and opportunities;
- user involvement that is still more often tokenistic and ineffective than making possible user led change.

We encountered many really positive developments in our projects at local level on the ground, examples of good practice, examples of workers showing enormous commitment against the odds - despite poor pay and conditions, lack of support and supervision. But the fact we found all these positives should not be used as an argument or, indeed, excuse - as it often has been in the past - for not addressing the fundamental barriers that more and more seem to be facing in social care and getting in the way of real personalisation, or person-centred support.

And these fundamental barriers emerge as the chronic under-funding of social care and the inherently defective dominant culture of social care. Both of these stand root and branch in the way of ensuring person-centred support for all; for mental health service users, people with learning difficulties, with chronic and life limiting conditions, drug and alcohol problems, with physical and sensory impairments, people who are old and physically or mentally frail. Just changing the delivery system from services to cash payments, not surprisingly, does not overcome this.

Instead what we encountered over and over were service users of all kinds and all ages, not having their needs met and routinely having their civil and human rights restricted and undermined; where social care is reduced to personal maintenance; where help if it comes at all, too often comes at the last minute.

All this cannot be stressed enough. What was good about the system we explored and worked with were the people within it. What was bad essentially was the complex relation of many years of under-funding and an outdated institutionalising means and needs testing culture.

And now of course we can expect things to be made even worse by the current massive cuts being imposed from the centre on social care, in benefits and broader public services and employment, with social care service users being stigmatised more and more as dependent and scrounging. The recommendations of the Dilnot Commission and the hesitant response to them so far from the Coalition Government do not encourage any confidence that these nettles are really going to be grasped and a sustainable system of social care made possible, which will ensure equity and independent living for all – both older people and service users of working age.

I feel being involved in the Standards We Expect project has been a privilege and a culmination of my working life. It has felt so important, not only because it has been a big, long, demanding and successful project, but because of how we have done it and who we have prioritised to listen to – which seems to me vital if we are to get social care and social support out of the backwater of neglect where it still is and has long been. This is crucial if it is to command the political and policy priority that must be key for a sustainable future – both for the policy and for us – as more and more of us come to need social support. This will be true as we live longer and more of us with impairments are able to live lives and our rights increasingly cannot be ignored or denied. We sought in the project to put the perspectives of service users, carers and practitioners first and that is what future policy must do. We will not resolve the problems facing social care, service users and their families by coming up with yet more unsupported promises of 'better for less'.

What I still find difficult to understand, and to deal with, is that a policy of such fundamental and growing importance to so many of us as social care is, can still be treated both politically and in policy terms as marginal. When the situation for many is so dire, so uncertain, so risky – in real terms – how is it there seems to be, relatively speaking, so little real political interest in such a large and growing proportion of our population. Are their rights and needs really that inconsequential?

Our project reinforced the view that really great and imaginative things are possible to support people in person-centred ways; which make possible that crucial unification between health, social care, housing and other mainstream services. There is truly a massive matter of work needed to speak truth to power – that many of us have as yet been unable or failed to do. There is a crucial task and responsibility of ensuring that the direct views, ideas, experience and proposals of people centrally involved should be a key shaper of policy and practice in a meaningful process of co-production. We have a long way yet to go to make that happen. We hope the findings from the Standards We Expect project can help by providing one more brick in the wall.

In her 2011 study, Catherine Needham frames personal budgets and personalisation in terms of the competing views of its 'advocates' and 'problematisers'. She reports that she is reassured to have held on to her 'ambivalence' about the issue (Needham, 2011, p.4). However, being ambivalent about a highly ambiguous development such as personal budgets and personalisation seems a doubtful position to hold. Very many service users feel harassed and oppressed by the way that the policy has been extended and implemented, often without effective choice or involvement. If personalisation is to have a progressive rather than reactionary future, then we may expect it will need to associate itself much more closely with the founding principles of the independent living and disabled people's movement, and the kind of values and definition that the Standards We Expect project found service users, carers and face-to-face practitioners attached to it.

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Notes on Contributor

Peter Beresford OBE is Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University. He is Chair of Shaping Our Lives, the national user controlled organisation and network of service users and disabled people. He has a background as a long-term user of mental health services and has had a longstanding involvement in issues of participation as activist, writer, researcher and educator.

Address for Correspondence

Professor Peter Beresford
Director of Centre for Citizen Participation
Mary Seacole Building
Brunel University
Uxbridge
UB8 3PH

Email: peter.beresford@brunel.ac.uk