How can the benefits of personal budgets for people with mental illness be sustained after the payments stop?

Naomi Clewett[1], Sarah Hamilton[1], Paulina Szymczynska[2], Jill Manthorpe[3], Jerry Tew[4], John Larsen[5] and Vanessa Pinfold[1]

[1] The McPin Foundation, London
[2] Unit for Social and Community Psychiatry, Queen Mary University of London
[3] Social Care Workforce Research Unit, King's College London
[4] School of Social Policy, University of Birmingham
[5] Drinkaware, London

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Abstract

One aim of mental health social work is to promote recovery and independence for people accessing services. Personal budgets, which can now be requested by all mental health service users in England, can enable service users to achieve these outcomes. This paper addresses the lack of evidence on service user understandings of the purpose and duration of their personal budget, and their experiences of personal budgets ending. We draw on interviews with 53 mental health service users and 28 practitioners. We identify how different factors affect the sustainability of the outcome: the type of outcome identified, how far service user and practitioner understanding of outcomes are shared, and the ability to continue activities after the budget ends. We draw out learning for practitioners and policy makers on improving the sustainability of outcomes achieved through personal budgets, and improving service user experiences of their endings.

Keywords: personal budgets, mental health, outcomes, payment

Background

Evidence shows that the use of personal budgets in mental health social care may lead to positive outcomes for service users. The evaluation of the personal budget pilots in England found that personal budgets increased wellbeing for people using mental health services, but that the uptake among mental health service users was low compared to other groups (Glendinning *et al.*, 2008). Similarly, a recent systematic review of personal budgets for mental health indicated potentially positive outcomes for choice and control, improved quality of life and reduced use of mental health services – although the quality of evidence was not strong (Webber *et al.*, 2014). We have reported elsewhere the important role that personal budgets may play in improving outcomes within the context of fluctuating health and changing lives (Larsen *et al.*, under review).

However, debate around personal budgets has largely focused on assessment, systems for allocating resource to individuals, and the choice of purchases made, while less attention has been paid to the process of ending personal budgets. The Care Act (2014) highlights the need for the review of personal budgets and for changes to budgets if individual circumstances change. The process of such reviews – particularly when it results in the withdrawal of support – is an important aspect of social care practice and the impact on the individual service user is largely unknown. Importantly, an outcomes-focused approach encourages both the individual and the funder to assess the effectiveness of the purchased support in meeting those outcomes. If the outcome is focused on change, once that change has been achieved, further support may or may not be required to sustain it. Equally, if a change outcome is not met, this may suggest that the support provided is not appropriate or effective and should be stopped or replaced by an alternative. However, if the outcome is to maintain wellbeing or participate in the decision-making process and management of care, meeting the outcome may be an indication that the support should continue. Nonetheless, the review process may result in stopping personal budgets that have been effective in maintaining good health.

The 2014 Care Act places a responsibility on English local authorities to prevent, delay and reduce the need for care and support of adults within their boundaries (Care Act, 2014). This provision has both an economic and a value based foundation; on the one hand there is a need to reduce the costs of providing social care support, on the other, there is recognition that health and social care agencies should promote independence and self-management. One important way that local authorities are permitted and now expected to meet adults' social care needs is by allowing choice in their care through a personal budget. Personal budgets became government policy in 2007 (Department of Health, 2007) and are enshrined in the 2014 Care Act. The local authority calculates the amount of money that an eligible individual is entitled to in order to meet their assessed social care needs. Service users are then able to make decisions, alongside the local authority, about how to spend that money to best meet their needs. Depending on their circumstances and wishes, service users may receive the personal budget as a direct payment, through which they receive the money themselves to spend on support that they individually arrange or purchase. Alternatively, the money can be managed by the local authority but used to purchase support according to a plan agreed with the service user or by a proxy, such as a family carer. Much has been written about personal budgets (see Needham & Glasby, 2014, for an overview). This article addresses an under-reported area: what happens when a person's personal budget funding stops.

There is increasing recognition that social care provision should not foster dependency on services, but rather should help individuals to set and reach goals that will allow them to live their lives and manage with as much independence as possible (Fine & Glendinning, 2005). This requires definable, personalised goals and measurable outcomes. Instead of being an ongoing means to address a care need, publicly funded social care support is increasingly intended to be a time-limited mechanism to recognise and build an individual's skills and capacity to manage independently (Heginbotham & Newbigging, 2013). Because adult social care is based on models of shared decision making, and collaboration between practitioner and user (Needham & Carr, 2009), the practitioner clearly has an important role in setting these expectations.

The last decade saw a shift in policy attention from needs-based, to outcomes-focused assessment and services (Miller, 2010). Outcomes-focused services are closely associated with 'personalised care' through the move towards tailored packages of support based upon an individual's own assessed needs and preferences, of which personal budgets are one important part. Glendinning *et al.* argued that 'outcomes are by definition individualised, as they depend on the priorities and aspirations of individual people' (Glendinning *et al.*, 2006, p.v). However, they also made the point that outcomes do not necessarily need to be associated with a *change* in the individual's needs or circumstances; they may be about *maintaining* a quality of life or levels of wellbeing and they may be about the *process* of deciding on and receiving support.

It is also important to acknowledge the impact of the reduction in available resources within local authorities that limits budget availability. It has been suggested that personal budgets may save money for local authorities (Leadbeater, 2008; Duffy *et al.*, 2010; Needham, 2011), although this has been criticised (Beresford, 2011; Slasberg *et al.*, 2012). However, the significance of potential cost-efficiencies in social care remains high as local authorities find themselves in ever tighter financial circumstances (Local Government Association, 2014). Whether or not these financial pressures influence individual assessments and decisions, they do provide a context for service users' understandings of reductions to services.

In practice, the increased interest in change outcomes raises an important question for social care practitioners and policy-makers: how is the transition made from providing support to meet a person's goals to withdrawing support because it is no longer needed? In this paper, we explore the experiences of people with a severe mental illness who had received, or were receiving social care support purchased through a personal budget, and the perceptions of practitioners who work with them. While other aspects of these experiences have been discussed elsewhere (Tew *et al.*, under review; Hamilton *et al.*, under review), here we focus

specifically on the factors that influence individuals' experience of personal budgets coming to an end: the understanding of the purpose of personal budgets, how far practitioners and service users share this understanding, and the process of ending a personal budget. Drawing on participants' experiences, we consider the impact of managing endings on the individuals, and look at how outcomes are sustained (or not) after a personal budget is no longer available.

Methods

This study took a longitudinal qualitative approach using repeated in-depth interviews with people who received a personal budget for mental health related social care needs and single interviews with mental health practitioners. Local research governance and national research ethics approvals were received for the study (Camberwell St Giles National Research Ethics Committee ref. 11/LO/0620).

Sites

Four English local authority sites were recruited to take part in the study. The sites were diverse and included two sites from the north and two from the south of England, two urban, one semi-urban and one rural site. One of these sites was unable to support recruitment within the time available due to delays in implementing personal budgets in mental health. As a result no data from this site is included. To protect participant confidentiality, sites are referred to as A, B and C in this paper.

Recruitment

Potential service user participants were identified through the local authorities or local voluntary sector organisations. In all cases care coordinators were contacted first to confirm eligibility and make the initial approach. If the service user agreed, their care coordinator passed on their contact details to the researcher who sent written information and spoke to the individual on the phone to explain the study. If they then agreed to take part, interviews were arranged at a time and location convenient to the individual and written consent was taken at that point. Mental health practitioners in all the sites were approached via email, phone and through researcher visits to team meetings. Practitioner interviews were conducted over the telephone to reduce their time commitment and maximise recruitment. Interviews were arranged at a time convenient for participants and consent was recorded both verbally and via email.

Participants

A total of 53 service users were interviewed. Participants were eligible if they had received mental health services for a severe mental illness and if they had experience of applying for or receiving a social care personal budget. Participants were defined as having a severe mental illness if their local authority social care team assessed them as having high needs. Service user participant characteristics are shown in **Table 1**. A total of 28 practitioners were interviewed. Practitioner characteristics are shown in **Table 2**. Where reference to individuals is made in the findings, pseudonyms are used.

Data collection

Where possible we interviewed service user participants twice (n=17) or three times (n=18) during 2012-13 allowing us to record how changes in their lives, their care and their mental health were interrelated. Practitioners were interviewed once. Topic guides were developed with input from a group of service user advisors (people with mental health problems and carers), who were recruited through service user-led organisations in each of the study sites. All interviews were conducted using a semi-structured topic guide (see **Appendix 1**, **2** and **3**) that was flexible in allowing the interviewer to respond to the participant's account. With consent, interviews were audio recorded and transcribed verbatim. Where consent to record was not given, detailed notes were taken during the interview.

Table 1. Participant characteristics – people accessing mental health services.

		N	%
Age	Mean	44	
	Range	21-71	
Gender	Male	20	38
	Female	33	62
Diagnosis	Schizophrenia & other psychotic disorders	14	26
	Bipolar disorder	14	26
	Depression	8	15
	Personality disorder	4	8
	Other	2	4
	Multiple diagnoses	7	13
	Missing data	4	8
Site	A	11	21
	B	31	58
	C	11	21

Table 2. Participant characteristics – Mental Health Practitioners.

		N	%
Gender	Male	12	43
	Female	16	57
Professional background	Social Worker	11	39
	Occupational Therapist	8	29
	Community Psychiatric Nurse (CPN)	9	32
Research site	Local Authority A	9	32
	Local Authority B	10	36
	Local Authority C	9	32

Analysis

The analysis was conducted using an *Interpretive Framework Approach* (Ritchie & Spencer, 1994) as it allows for simultaneous analysis across both themes and cases to identify patterns and retrieve data easily. This approach provides a method for systematic thematic coding, using a matrix to provide transparency and to make gaps in the data apparent. Four members of the research team familiarised themselves with the data and established an initial framework designed around research questions and emerging themes. Service user advisors independently coded example transcripts and following a consultation meeting the coding framework was revised. Transcripts were divided between the researchers for systematic coding which was reviewed again to ensure consistency and to check whether themes had changed or new themes developed. Having agreed a final framework, transcripts were coded, collated and summarised using the software NVivo 9. A matrix containing summaries of each coded quote provided transparency in the representation of agreements and contrasts within data.

In this paper we focus on the service user experiences of endings, and how these related to influencing factors. Practitioner data are drawn upon where they provide further insights and explanations for local practices. Data addressing themes around understandings of the purpose of personal budgets, anticipating endings, and experiences after endings were extracted and analysed within each theme to identify sub-themes and links between data. Findings are drawn from analysis across all 53 service user interviews and 28 practitioner interviews in the discussion of the understanding of personal budgets and perceptions of endings. Only 13 service users interviewed had experienced a personal budget ending, and this data was analysed alongside practitioner data to investigate their experience of endings. We have provided three illustrative case studies (see boxes) which demonstrate how the combination of the understanding of personal budgets and the personal budget process may impact upon the experience of endings within an individual's life context. Whilst acknowledging that the term is problematic for some (Dickens & Picchioni, 2012), we use 'service user' here to refer to the participants in the study who had used or were using mental health services.

Findings

How far the benefits gained from personal budgets were sustainable after the payments were stopped was influenced by a) the extent to which personal budgets were initially presented and understood as outcomes focused – including whether specific outcomes were identified and whether these were change outcomes – and b) the extent to which there was agreement between the practitioner and service user about whether they had achieved their outcome and whether a personal budget was still required.

How far are personal budgets understood to be outcomes-focused?

In data from practitioners and all 53 service user participants we found considerable variation in both service users' and practitioners' explanations of the general purpose of personal budgets. Some practitioners described them in relation to addressing an 'unmet need' (Community Practice Nurse (CPN), Site B). Many, however, talked about personal budgets as a means of achieving a goal or outcome. While a few identified maintenance outcomes as being an acceptable use – i.e. to sustain an individual's wellbeing 'for life' (Social Worker, Site A), most practitioners emphasised the need to address change outcomes. Often this was associated with a commitment to recovery-focused practice:

> *It's also about enabling us to put a package together with all concerned to best enable [service users] to move on, support them in their recovery, in their rehabilitation in the community, preventing relapse.* (CPN, Site D)

A few practitioners suggested there had been a shift in the local authorities' approach to personal budgets to emphasise the need to focus on change outcomes:

> *I think there were various different phases of direct payments. One which was: 'hey, there's this money, go and spend it' […] And then other workers were being told to go out and say: 'actually, no, […] this has to be attached to the recovery plan, it has to be showing clear goals and change'.* (Social Worker, Site A)

It was widely understood among practitioners that to get a package of support approved by the local authority, clear links had to be made between how a personal budget is spent and individual goals in the user's plan. Moreover, depending on the perception of financial pressures, practitioners were also likely to believe that costly or long-term budgets would not be approved and that goals should be achievable within a relatively short time. In some cases practitioners fully supported the local authority stance, while in others they aligned themselves with the service user in supporting them to get the most out of the system by tailoring plans towards these types of outcomes. Several practitioners stated their assumption that when budgets were reviewed they would most likely be reduced and eventually ended once outcomes had been achieved.

This understanding was shared by some service users who saw their personal budget as a way to increase their independence and reduce their need for support. Those who fell into this group often described a clear and measureable change outcome which they felt could be achieved through the support they purchased with their personal budget. Anne's case (**Box 1**) is an example of this approach.

Sixteen participants identified goals intended to increase independence, for example, learning to cook, driving lessons and confidence to go out independently:

> *I wanted to go out more on public transport that was one thing I wanted to do, to walk on my own from one place to back home or one place to another.* (Service User 5, Site C)

> *The end goal is to stand up on my own two feet, mentally and emotionally, for the first time in my life.* (Service User 16, Site B)

For others, the personal budget allowed them to address areas that they struggled with by employing others to do this, including through Personal Assistants (PAs) and cleaners, and through hobbies or social activities. Rather than seeking change in the individual's circumstances, this addresses a maintenance outcome, through which the person's quality of life is maintained as long as that support is available.

A small number did not identify outcomes at all but perceived the personal budget as additional income which they were entitled to as a result of their mental health problem, without linking this to an identified goal.

> *There won't be any revelations or anything new to my life. I'll be in a better financial position, but that's about it.* (Service User 14, Site B)

Practitioners recognised the difficulty some faced in understanding personal budgets as outcomes-focused and time limited.

> *I think often clients think it's for life. I can think of one, maybe two […] clients in the team that have that expectation, and it's been quite difficult to say to them that that's not the case: it's to bring about some goal or aim, and then once that's been achieved to then… that it needs to be stopped.* (Occupational Therapist, Site A)

Some practitioners thought that personal budgets should not be used for ongoing activities because they 'created a dependency' (CPN, Site B) when it was not feasible to fund them indefinitely. Indeed, both service users and practitioners agreed that where ongoing activities are paid for with no sense of change being achieved, benefits were much less likely to be sustained after the payments stopped.

> *Because you can see how it benefits them at the time, something like horse-riding lessons, but it's that worry that when it stops, what do they do then? They've not got the money to carry on themselves, so they're a little bit back to where they were before.*
> (Social Worker, Site B)

Ending types

Drawing on data from 13 service users who experienced personal budgets ending, and practitioner experiences, three types of ending were identified:

1. **Personal budget not renewed following a review** – frequently the personal budget was reviewed after a period (often, but not always one year). For some, the result of the review was that a personal budget was no longer needed or that the person's needs had changed and they were no longer eligible. This sometimes happened over a number of reviews through which the budget was reduced to create a tapered ending. This was the most common anticipated and actual ending of a personal budget for our participants. Nine service user participants experienced this type of ending.

2. **Service user chooses to end their personal budget or not to re-apply following review** – this was not common, but occurred for several reasons: the budget was no longer benefitting them, they had outgrown the need for this support, they preferred traditional mechanisms of support, or they were too unwell to continue using the budget as intended. Three service user participants experienced this type of ending.

3. **Personal budget stopped early due to misuse of funds** – only one service user participant experienced this in our study, and another had their budget reduced. Although rare, this was experienced by service users as a punishment.

The type of ending was characterised by the relative power and control of three key agents in decision making: the service user, the practitioner, and local authority managers.

When choosing to end their own budget, clearly the service user takes control of decision making, albeit within the limitations of their own capacity and knowledge about the possibilities of personal budgets. One service user ended their personal budget as they felt they no longer had a need for it, two others were not happy with the care they were receiving. In the latter cases there was evidence that their decision might be different had they been aware of the option to change their provider. In contrast, budgets stopped early were being reduced/ended in line with local authority rules about restrictions on budgets. However, how far the service user had understood and agreed to the rules about spending was unclear given apparent levels of confusion and disagreement with the decision.

When personal budgets are reduced or ceased following a review (the most common type of ending), control over the decision is less clear. Although the review process is intended to be person-centred, both service users and practitioners were aware of the power held by the practitioner as gatekeeper of funds (see Hamilton *et al.*, 2015, for a full discussion on choice and control with personal budgets), and the restrictions in place through local authority policies. Anne's case study (see **Box 1**) may be seen as a positive example of this type of ending; following a review, Anne and her practitioner agreed that the personal budget was no longer needed. This agreement was facilitated by earlier explicit conversations about the personal budget ending. However, in several instances service users did not agree with the decision that

their personal budget was no longer needed to achieve their goals. They perceived that the real reason for ending the personal budget was the local authority's need to make financial savings. This was often associated with a broader impression that support and benefits were being cut. Some, like Arthur (see **Box 2**), felt 'resigned' to the idea that due to 'austerity in cuts in the NHS, […] funding for me had to stop' while others felt angry and de-valued.

Many practitioners voiced similar concerns about local authority cuts, citing reductions in the size and number of personal budgets being approved in response to tightening local finances. Some reported being under pressure to reduce or end personal budgets:

> *I mean, the impact is that they'll get less, get a smaller budget ultimately. I think we are starting to be more targeted […] we are in the world we're in, which is one of budgets and shrinking resources, so, yes, I think we have got a responsibility to govern those resources and try and target those resources.* (CPN, Site B)

Within the context of perceived and real pressure from the local authority, practitioners and service users negotiated the process of endings.

Box 1. Anne (Site A) – A positive move to independence

At the time of applying for a personal budget Anne had four children and was feeling very low. With her practitioner, she identified a need for therapy but was unable to attend appointments because of childcare needs. They agreed to apply for a direct payment to pay for childcare to enable her to attend therapy. Anne had a very clearly defined understanding of what the purpose of the budget was, and when it would end, from the outset:

> ***I only wanted it for a specific purpose. I do know of other people that have used it for other things, but I wanted it for a specific purpose, to pay for childcare so I could go to my therapy […] I just took it that, if I got better, when my therapy was finished it would stop, because I would stop needing to go and that would be that.***

The identified change outcome was to manage her mental health through the benefits gained through therapy and the link from her use of the personal budget to this outcome was explicitly drawn.

> ***I was on the verge of getting sectioned, so if I hadn't had the direct payment and been able to access my therapy, nobody knows what would have happened.***

The point at which the personal budget would end was openly discussed from the initial application.

> ***We were talking about when we should let them know to finish it, when I was going to be finishing [the therapy] and all that kind of thing, and I didn't need it any more.***

At the point of our last interview with Anne, she was working part-time and studying. She continued to draw on techniques from her therapy to help her with negative thoughts. The ending of the budget coincided with the ending of her therapy, which, although daunting for her, was viewed as a positive move to independence.

Box 2. Arthur* (Site A) – A struggle to maintain benefits after the personal budget ended

Arthur had little information about personal budgets before beginning to receive one, and was led by his social worker, deciding to 'go with the flow'. He understood that the payment was meant 'to cover activities which we deemed would be very therapeutic for my mental health', including yoga, Tai Chi and art classes. He found this 'incredibly therapeutic' saying it brought his symptoms under control as well as '[keeping] myself occupied' and 'allow[ing] me to reduce my weight'. During the period of receiving a personal budget he 'wasn't quite sure when it would end, quite how much longer I had'.

Arthur understood that the personal budget was to be used 'as kind of a stepping stone, into sort of being able to earn my own money from it'. He remembers that he was told 'we'd like you to think about trying to provide these activities under your own steam, possibly by looking for work'. Arthur did not feel, however, that working was a realistic prospect for him at that time and he therefore struggled to continue to fund the activities. He described the ways he found to manage using his social security benefits to pay, including pooling funds with friends to save on food bills, using savings and receiving a discounted price from his yoga teacher. He said that 'I quite desperately want to be able to keep these activities going' but was 'having to tighten my belt quite a lot'. At the same time Arthur worried that his income would be cut further by changes to his benefits and he would no longer be able to do these activities at all.

By the time of the final interview Arthur was more hopeful that he would be able to cope with some part-time work or make some money by selling some of his art work.

Change outcomes and endings

The most positive endings were found amongst service users who shared an understanding of change outcomes with their practitioner, and were able to achieve their outcomes during the time they received their personal budget, and therefore continued to benefit from the budget after it ended. This occurred in four cases out of the 13 participants whose budgets ended. Changes that could be sustained without support tended to involve change in relation to skills, confidence or qualifications.

> So, it was a very good thing in my life but I feel now that I've moved on from it, that I am back to, not wholly back to my old self. But my point was that I don't feel like the sort of person that needs [a personal] budget at the taxpayers' expense anymore.
> (Service User 19, Site B)

In Anne's case (**Box 1**), she identified a clear purpose for the personal budget with a natural end point when her goal of developing self-management techniques through therapy had been reached.

Maintenance outcomes and endings

For service users who had identified maintenance outcomes, sustaining change after the budget ended was more difficult. As the benefit of the budget was in the ongoing activities it funded, the emphasis for these service users was on finding a way to continue activities and maintain this outcome, rather than moving on.

Several service users sought to fund activities themselves. For some, this became possible because of the benefits of the personal budget itself, for instance getting the person back into work and earning. This enabled them to continue with activities to support their day-to-day wellbeing that were previously covered by their personal budget.

Arthur's experience (see **Box 2**), however, demonstrates the difficulties that some faced in attempting to fund activities themselves. In this case, maintaining activities was possible only through compromising on other areas of spending.

For others, who could not afford to continue chosen activities, the only solution was to reduce or stop activities altogether. When activities were relied upon for daily wellbeing, it was difficult to sustain the same level of wellbeing once these activities were removed from an individual's life:

> *So we still did some of it, we just did less of it, because I couldn't... I can't afford to do it all the time. And it's funny, there was definitely a noticeable slowing of my improvement, because I couldn't practice quite so often.* (Service User 6, Site A)

In these cases, the end of a budget was often associated with a great sense of loss, and frustration that something helpful that they relied upon was being withdrawn. In Helen's case (see **Box 3**) her understanding was of a maintenance outcome, she had not planned or agreed to an ending, and therefore could not see how her wellbeing could be maintained once the budget was withdrawn.

Box 3. Helen* (Site B) – Deterioration of mood following the end of personal budgets

Helen received a personal budget for about 2 years and was interviewed before and after it ended. On the one hand she saw it as a way to improve her social inclusion and quality of life, using the money to fund trips to visit relatives, alternative therapies and home improvements. She described how having the personal budget made her feel good as she was going out to see people again. However, she did not have a clear goal articulated and did not have a plan for sustaining these benefits beyond the personal budget; receiving the money in itself made her feel 'cared for'.

Helen linked her ongoing wellbeing with the activities funded by her personal budget. Consequently, the 6 monthly reviews prompted considerable anxiety as she was worried that the support would stop. Helen said that after her last review the money stopped coming into her account, and shortly afterwards she was also discharged from the secondary care mental health team.

Following the end of her personal budget, Helen was not able to visit family as often as she used to and said that she *'felt a bit depressed and down again. It's back to I can't go out again […] I just feel fed up […]. I cannot afford mentally to stay like that'*. She attributed the deterioration in her mood with her inability to continue activities that maintain her wellbeing. Helen could not understand the reason for her personal budget ending, particularly as she felt that it was actually saving the NHS money.

Generally maintenance outcomes required resources from the service user if they were to be sustainable after budget ending, however, there were some exceptions. In areas where there is a good variety of free or accessible local resources, practitioners may be able to find alternative means of support for service users to fill the gap after a budget is withdrawn. In reality, there was little evidence of this happening within our sample. There was, however, evidence that some one-off payments were being made to support long-term maintenance outcomes. For example, one service user purchased a laptop to contact family and friends abroad, reducing their social isolation. However, some who made this type of purchase were concerned about what would happen if the item broke or needed replacing.

Discussion and recommendations for practice

Our findings and the case studies presented here illustrate the variation in approach to personal budgets and to managing their ending. In mental health at least, our data shows that for some, personal budgets are increasingly used as short- or medium-term interventions, not as indefinite sources of support. How this is explained to service users and the management of the transition from personal budgets may affect the ability to sustain any benefits achieved through this support.

Many service user participants were unclear about the purpose of personal budgets and did not understand them to be outcomes-focused. This was further reflected in the accounts of some practitioners who described that the emphasis had changed over time. This was compounded by a belief that support was being withdrawn as a result of government cuts.

Accounts in our data suggest that the outcomes debate has prioritised change outcomes over maintenance outcomes for people with severe mental illness. While participants felt that personal budgets were effective in maintaining mental health and wellbeing, these benefits were generally not sustained after the money ended, nor were alternative sources of this support provided. Moreover, a long-term goal taking years to achieve may be viewed as a less efficient use of local authority funds and terminated early.

Given this emphasis in practice on relatively short-term change outcomes goals, our findings suggest that greater attention needs to be paid not only to the benefits to be achieved through a personal budget but also to how these can be sustained after the money is no longer provided. Characteristics of the most effective ongoing budgets identified in our study are that: a) the service user and practitioner both understand the personal budget is to be used to meet an agreed goal or outcome; b) both understand that the personal budget will be reduced or ended once/if that goal is met; c) both agree that the goal has been met at the point when the personal budget ends; and d) some plan is in place for sustaining any benefits before the budget is ended. When communication between the local authority and the individual was good, and both parties agreed on their goals and how to measure success, endings were viewed as a positive step towards independence. Where these were not in place, the loss of support through a personal budget often meant that benefits were not sustained and even caused people additional difficulties and distress.

Our findings also contribute to the debate around whether social care should be needs-based or goal-led (Foster *et al.*, 2006; Trevillion, 2007). Participants who used personal budgets to maintain their wellbeing and who experienced an improvement in their mental health as a result found themselves no longer eligible for support. Cases like that of Helen show how this mechanism may contribute to a 'revolving-door' effect in which people's health declines, increasing the need for further intensive support again. In order to prevent people repeatedly re-entering the system, this study shows that either there should be resources allocated to continually fund support that maintains mental health, or that other, more sustainable sources of support are found – either through mainstream free and affordable local services, or through a different kind of purchase from a personal budget. The purchases made through personal budgets in this study demonstrate how, for some, they may be used as a preventative tool and

reduce the demand on health services in the future. To achieve this, attention should be paid to how this kind of support can be maintained longer term, in line with the commitments in the Care Act 2014 to 'prevent, delay and reduce needs'.

The strength of our study is the longitudinal, qualitative approach enabling us to capture not only the use of personal budgets but also the impact on the service user after the personal budget ceased. We drew on data from both service users and practitioners. However, this study is limited by the sample size, in terms of the number of local authorities and the number of participants. While drawing on 53 accounts of personal budgets and service users' beliefs about their purpose and feelings about ending, only 13 of these actually finished using a personal budget within the data collection period. Furthermore, local authorities are constantly revising their implementation of personal budgets in response to financial and other pressures. As a result, caution is needed about generalising this study to wider social care practice. Despite this, the findings reported have potential value for both policy and practice.

Conclusion

The implementation of personal budgets in mental health comes at a time of increased focus on outcomes in social care and of tightening local authority budgets (Heginbotham & Newbigging, 2013; Local Government Association, 2014). This study demonstrates that sustainable outcomes from personal budgets are possible after the payments end if both service user and practitioner have a shared understanding of the outcome and a) it is a change outcome AND this outcome is achieved through the personal budget, or b) it is a maintenance outcome AND the personal budget can be replaced by other forms of finance or free local services or resources after it ends.

Our findings contain messages for both practitioners and policy makers around the purpose of personal budgets in mental health social care support, and the process of ending these. This includes the importance of clear guidance on the purpose of personal budgets for mental health teams, including the short- or long-term scope of personal budgets and the types of outcome considered appropriate. A more sophisticated understanding of the link between personalised care and outcomes-focused care, and between outcomes-focused and needs-driven support, is also called for. If personal budgets are intended to facilitate change outcomes and the aim is to end support after a specific goal is met, their use for long-term maintenance of mental health may be questioned. Alternatively, if maintaining mental health and wellbeing is considered a legitimate use of personal budgets, longer-term commitments to personal budgets for individual service users could reduce anxiety and support sustained wellbeing. Regular reassessment may mean that people who are benefiting from personal budgets to improve their mental health no longer receive them. In these cases, plans for sustaining outcomes beyond the provision of a personal budget, whether through self-funding, alternative (free) provision or reducing need should be a policy priority to ensure that personal budgets represent good value long-term.

For practitioners, these findings emphasise the importance of clarity about the purpose and duration of personal budgets in initial and subsequent discussions with service users. This should lead to a discussion of realistic goals and an agreement of what progress and achievement will look like. In this way, personal outcomes can be framed positively and the end of the personal budget may be more likely to be experienced as an achievement. Where personal budgets are funding ongoing activities, planning for the ending should include discussions about either how activities will continue, or how the benefits of these activities might be maintained after the payments stop. This may include signposting to alternative and free of charge community resources.

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Notes on Contributors

Naomi Clewett is a Senior Researcher at The McPin Foundation, a mental health research charity. She has conducted research across a range of social and mental health issues, most recently on personal budgets, stigma and women with complex needs. She has a particular interest in qualitative research and involving people with lived experience in the research process.

Sarah Hamilton, PhD, MA, BA, is Research Manager at The McPin Foundation, a voluntary sector research organisation focusing on research delivered in collaboration with people with lived experience of mental health problems. She has conducted research and evaluations across a range of mental health and social care topics. Her main expertise is in qualitative research and she has a particular interest in communication between service users and professionals.

Paulina Szymczynska is currently pursuing a PhD in Social and Community Psychiatry at Queen Mary University of London on the subject of participation in mental health clinical trials. She is also a Graduate Teaching Assistant on a Dementia Studies course for health and social care professionals in Scotland and works as a Consultant on a range of research and academic projects with organisations across the UK. She previously worked as a Senior Researcher at the McPin Foundation based in London on a number of different projects concerned with service user involvement and mental health issues.

Jill Manthorpe is Professor of Social Work and Director of the Social Care Workforce Research Unit at King's College London where she conducts policy and practice research for the Department of Health and other funders on ageing, dementia, social care and its interfaces. She is Emeritus Senior Investigator of the NIHR and Chairs the Department of Health's Policy Research Programme Commissioning Panel.

Jerry Tew is Reader in Social Work and Mental Health at the University of Birmingham. His professional background is as a mental health social worker and he co-founded the Social Perspectives Network which promotes a vision for mental health practice that emphasises the centrality of issues of social identity, participation and relationship. He is the Director of the Family Potential Research Centre and is currently coordinating an ESRC funded programme of knowledge exchange around family inclusive policy and practice after 'Think Family' with a broad range of Local Authority, NHS and voluntary sector partners.

John Larsen, PhD, MA, BA, is Director of Evidence and Impact at the alcohol harm education charity Drinkaware. He was previously the Head of Research and Evaluation at the charity Rethink Mental Illness, where he was the Principle Investigator on The People Study reported on in this paper. John is an Associate Editor of the *Mental Health Review Journal* and a Visiting Researcher at the Department of Health Service and Population Research within the Institute of Psychiatry, King's College London.

Vanessa Pinfold, PhD, is the co-founder and Research Director of the McPin Foundation, a mental health research charity in the UK. Vanessa is an experienced health services researcher recently working on wellbeing networks and recovery, evaluation of anti-stigma initiatives and development of public and patient involvement research programmes within complex intervention studies.

Correspondence

Naomi Clewett
The McPin Foundation
32-36 Loman Street
London
SE1 0EH

E: naomiclewett@mcpin.org
T: 0207 922 7876

Appendix 1: Service user topic guide – Time 1

1. What is your current situation with receiving Personalised care?

a. Are you receiving/attempting to receive Personalised care at the moment? Could you elaborate?
b. And how long have you previously been in contact with services for?
c. What types of care and/or services do you access at the moment?
d. [If interviewee is accessing Personalised care] How was your care organised before you accessed Personalised services?
e. In what way does the care which you receive support your mental wellbeing?
f. How satisfied are you with your current support package?

2. What was your situation before you were offered Personalised care?

a. Living circumstances?
b. Social wellbeing and quality of life, including relationships?
c. Health status?
d. How did the services which you were receiving meet your needs?

3. How did you first hear about personalised care? [Was it through your CPN? Through a forum? Through the media? Etc.]

a. Who referred you [Care coordinator? Social worker?] and what information did they provide?
b. How long did you have to wait for your referral to be dealt with?
c. Have you been kept informed about the status of your application?
d. What did you expect in terms of the referral process?
e. How in control did you feel?

And now we're going to move on and talk about the support planning process. If the interviewee is not yet in receipt of Personalised care, move to qu. 9.

4. Could you describe the process of being assessed for Personalised care?

a. Which practitioners and services did you work with? In what ways did they guide you through the process?
b. Who else supported you [family, friends, peers]? And in what ways?
c. How long was the process?
d. How was your relationship with your support planner?
e. Were you offered a choice in terms of who conducted the planning?
f. How did you reach a sense of what your needs or outcomes were?
g. How did you feel about the process?
h. What could have been done better?
i. Were you offered choice/given options?

j.   Were possible changes in your health or mental wellbeing considered in the planning process?
k.   Was a broker involved in the process? If so, what role did they take?
l.   Were you made aware of how funding for your direct payment/personal budget would be calculated?
m. Could I possibly see your care plan?

5. How do you manage and spend your budget?

a.   Were you given a figure for how much money you would receive? How accurate was this?
b.   Was there any negotiation around that? If so, could you explain?
c.   Were you satisfied with the amount of money budgeted? How did it fit with your expectations?
d.   Did somebody help you with the accounting process?
e.   How much choice were you given in how, and where you spent your money?
     [i.e. if you have a PA, were you given the opportunity to choose who you wanted to employ?]
f.   In terms of holding your own budget, what worked well, and what could have been organised better?

6. Have you had a review since you have been accessing Personalised care?

a.   How frequently does this take place?
b.   Have you considered asking for an early review?
c.   If you haven't had a review, do you know why?
d.   How do you find the process of being reviewed?
e.   Who is involved in the reviewing process, and what role are you yourself given?
f.   What seemed to be the main conclusions or changes about how you should manage your Personalised care?
g.   How did you feel about this?
h.   Were there any needs you felt you had, which were not addressed?

7. What affect has personalised care and support had on your life?

a.   What does Personalised care mean to you?
b.   What specific impacts has Personalised care had on your life circumstances?
c.   Has your access to Personalised care impacted on other people in your life?

8. How do you see your future, and the influence which Personalised care might have on your life?

a.   How do you think your life will look like in 6 months time? And beyond this?
b.   What are your aspirations?
c.   How will your support enable you to achieve these things?
d.   What might get in the way of achieving these things?

9. If you are not yet accessing Personalised care:

a. What stage in the application process are you? [Have you just heard about Personalisation? Have you been referred? Is your application being processed?]

b. To what extent do you feel that you have been kept informed about what will happen next, and at which point in time?

c. How have you found the process so far? What are the positives and what are the negatives? Is the process what you were expecting?

d. In what ways do you think that Personalisation could help you to achieve your goals?

e. In what ways do you think that accessing Personalised care, rather than the current system of care which you use, would benefit you?

f. If you were given a personal budget/direct payment, how would you like to use it to change your life?

Appendix 2: Service user topic guide – Time 2/3

1. **How have you been in the last 6 months?**

2. **Have there been any changes in your circumstances since Interview 1?**

   Have there been any changes in your life since we last met?

   > If yes – have they made you reconsider your personal goals and support needs?

   How has your health been in the past 6 months?

   Have there been any changes to your social care? (Identify causes, explore the effects)

   > If yes – has your personal budget been affected?

3. **How would you describe the progress with personal budget?**

   Specific questions regarding personal circumstances, based on T1 interview

   How do you feel about your progress in working towards your goals?

4. **How have you been using your personal budget? (Identify currently used support and services to compare with T1)**

   Have you been accessing any new services?

   Have you stopped using any services?

   Have there been any things that you haven't been able to do or achieve?

   What aspect of your budget have you been enjoying the most?

   How satisfied are you with the support you are receiving?

   In what way does the care which you receive support your mental wellbeing?

   How much in control have you felt?

5. **How would you describe your relationship with your care coordinator?**

6. **How would you describe your social wellbeing and quality of life, including relationships and social networks?**

7. Have there been any changes in the way you manage your budget (accounting process)?

8. Have you had a review since our last meeting?

How do you find the process of being reviewed?

Who is involved in the reviewing process, and what role are you yourself given?

What seemed to be the main conclusions or changes about how you should manage your Personalised care?

How did you feel about this?

Were there any needs you felt you had, which were not addressed?

9. What impact has Personalised care and support had on your life?

What specific impacts has Personalised care had on your life circumstances?

Has your access to Personalised care impacted on other people in your life?

10. How do you see your future, and the influence which Personalised care might have on your life?

How do you think your life will look like in 6 months' time? And beyond this?

What are your aspirations?

How will your support enable you to achieve these things?

What might get in the way of achieving these things?

Appendix 3: Interview topic guide – key worker interview

Introduction

Thank you for agreeing to speak to me today. The purpose of the interview is to explore your experiences of 'personalisation' as a care coordinator.

With your permission I will turn the recorder on now. You may wish to use examples from your work and if any names are mentioned, we will ensure these remain anonymous in our data. The recordings will only be listened to by our research staff.

Do you have any questions before we start?

Confirm the interviewee read and understood the consent form provided prior to the interview.

1. **'Personalisation' is a contested term and we are interested in how different people perceive it. What do you understand by 'Personalisation'?**

   Probes:

   - How does 'Personalisation' change the way social care is delivered? (If budgets not mentioned – introduce)

2. **When did you first start hearing the term 'Personalisation' used?**

   Probes:

   - How was it introduced? In what circumstances (training, guidance received)? How long ago?
   - What impact did you expect Personalisation to have?

3. **Has the way you work with clients been impacted by 'Personalisation'?**

   Probes:

   - Has this changed over time since the introduction of personalisation?
   - How? Describe impact.
   - Changes in relationships with clients?
   - Decision-making process around care planning?
   - Identifying needs/solutions.
   - Assessment/support planning.
   - Managing support.
   - Finance/resource changes.

   a) **Do you have clients on PBs etc.?**

   Probes:

   - How many, how long?
   - How did clients come to access it? (Did you introduce the idea to client, or did they ask for it etc?)
   - Why are some clients accessing PBs while others are not?
   - Are there clients who would have benefitted from PBs but don't access them? Why?

- How long do you expect your clients to remain on a budget?
- Have you had any clients who have come off a budget? How were they affected by this?

b) Can you think of an example where Personalisation works well and not?

Probes:

- Why?
- Severity of SMI?
- Outcomes?
- Identification, assessment?
- Risk?
- Area?

c) Have you had any requests for PBs to be spent on inappropriate things?

- What makes some things inappropriate and others not?
- How far do you think clients understand what is appropriate and not?

d) How confident do you feel around 'Personalisation'?

Probes:

- What is difficult? (Decisions you found hard, how do you manage risk e.g. safeguarding?)
- Need for support? (Specific support around working with people with SMI/ fluctuating conditions?)

4. What do you think about Personalisation?

 What do you think is the future for Personalisation?

 (integration)

5. What would you have found useful in your role in Personalisation?

 What do you think other care coordinators would have found useful in their role?

6. Is there anything else you would like to tell me?

Thank you!