

The effectiveness of personal budgets for people with mental health problems: A systematic review

Short title: Personal budgets systematic review

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Abstract

Background: Personal budgets are a key policy priority in adult social care in England and are expected to become increasingly important in the care of adults with mental health problems.

Aims: This paper systematically reviews evidence for the effectiveness of personal budgets for people with mental health problems across diverse outcomes.

Method: The review, conducted in 2013, used the EPPI-Centre methodology for conducting a systematic review informed by Social Care Institute for Excellence guidelines. Data were extracted from studies and combined using meta-synthesis.

Results: 15 studies were included in the review which found mostly positive outcomes in terms of choice and control, quality of life, service use and cost-effectiveness. However, methodological limitations make these findings rather unreliable and insufficient to inform personal budgets policy and practice for mental health service users.

Conclusions: Further high quality studies are required to inform policy and practice for mental health service users which lags behind other adult social care groups in the use of personal budgets.

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Introduction

The aim of personal budgets is to put people at the centre of their own care and support. A personal budget recognises an individual's strengths and preferences, and enables them to gain more choice in, and control over, the support they require to live their own lives. Helped in part by successful campaigning by disability rights groups and the Independent Living Movement, personal budgets have become a key health and social care policy in England (Department of Health, 2005, 2007; Her Majesty's Government, 2011).

Personal budgets have evolved in England since 2001 when Local Authority Adult Social Services Departments were required to offer eligible people cash direct payments to spend on care and support, which were frequently one-off payments for discrete items. 'Individual budgets' were subsequently developed, which were either a cash direct payment or a managed budget, or a combination of the two (Department of Health, 2005; Glendinning et al., 2008). These became known as personal budgets, which were rolled out throughout adult social care (Department of Health, 2007). However, widespread implementation has been accompanied by concerns that self-directed support (the process of support planning which elicits an individual's goals and how to meet them), which underpins personal budgets, fails to live up to its ambitions (Slasberg, Beresford, & Schofield, 2012).

The use of personal budgets by people with mental health problems has been consistently lower than for other social care groups (Audit Commission, 2010; Davey et al., 2007; Riddell et al., 2005). For example, in 2011-12 only 14.6% of eligible mental health service users received a personal budget, compared to 58.8% of people with a learning disability, 47.9% with a physical disability and 45.2% of older people (Health and Social Care Information Centre, 2013). Organisational arrangements for the provision of mental health social care in England may have hampered the delivery of personal budgets to people with mental health problems (Larsen et al., 2013). Social care funding is means-tested and even where NHS and social care

services are integrated, personal budgets require financial assessments and separate funding arrangements from NHS care (Audit Commission, 2010). Additionally, it has been proposed that there is a pervasive tension in mental health care between safeguarding against risk and the provision of user-directed care, which often involves some risk-taking (Carr, 2010). Consequently, mental health practitioners sometimes see people with enduring mental health problems as incapable of managing personal budgets (Carr, 2011; Taylor, 2008). Other barriers to implementation include the increased levels of bureaucracy that have accompanied personal budgets (Jacobs et al., 2013); concern amongst service users about managing personal budgets, and about the quality of support provided to help them with this (Newbronner et al., 2011; NHS Confederation, 2011).

Personal budgets may assist self-management programmes such as Wellness Recovery Action Plans (Copeland, 2002) by helping people to purchase services which support their recovery. Self-management is seen as increasingly important in long-term health conditions (Bodenheimer, 2003), and has become prominent in discourses of personal recovery in mental health services (Schrank, Bird, Rudnick, & Slade, 2012; Slade, 2009). Personal budgets also fit within current policy discussions about adult social care in England where co-production of services is becoming more common (Social Care Institute for Excellence, 2013). However, there are concerns that the marketplace for services and support to be purchased using personal budgets is under-developed which weakens their potential to work effectively (Spicker, 2013).

In spite of the low take-up of personal budgets to meet mental health social care needs, the Government have piloted personal health budgets for long-term conditions in England (Department of Health, 2009). Personal health budgets enhance choice and control over health care but, unlike social care personal budgets, are not means-tested. The evaluation of personal health budgets showed promising findings and they were particularly cost-effective for people with mental health problems (Forder et al., 2012).

Consequently, the Government has begun to introduce them into the NHS in England with plans to make them available in mental health services in 2015.

Despite the policy rhetoric, there is limited evidence about outcomes of personal budgets for people with mental health problems (The Health Foundation, 2010). Similar self-directed care systems such as 'cash and counselling' have improve satisfaction, service use and outcomes in the USA (Alakeson, 2010).

However, Carr & Robbins (2009) reported that internationally there were few other schemes available for mental health service users. Although a prominent strand of government social care policy in England, there have been no systematic reviews of the literature examining the effectiveness of personal budgets for people with mental health problems. Therefore, this review aims to synthesise the evidence – qualitative and quantitative – about the outcomes of personal budgets for people with mental health problems.

Method

This review used the EPPI-Centre methodology for conducting a systematic review (Gough, Oliver, & Thomas, 2012), informed by the Social Care Institute for Excellence (SCIE) systematic review guidelines (Rutter, Francis, Coren, & Fisher, 2010). The development and conduct of the review was further informed by an Expert Advisory Group (EAG) with a range of research and clinical expertise, including service users and carers.

The search strategy was agreed by the research team in consultation with the EAG and refined by pilot searches using potential search terms. The final list of search terms used in the review were: cash and counselling; cash for care; consumer directed care; direct payment*; indicative allocation; individual budget*; individual service fund*; managed account*; managed budget*; notional budget*; personal budget*; personal health budget*; personalisation; personalised care; personalization; person centred;

pooled budget*; recovery budget*; resource allocation system (RAS); self-directed assessment*; self-directed care; self-directed support; support plan*; and virtual budget*. Terms were adapted according to the search functions and syntax of each database.

28 databases were searched; citation tracking and web searching was used to identify potentially relevant studies; selected social care journals and industry publications were hand-searched; and studies suggested by the EAG and other researchers/clinicians working in the area of personalisation were also sourced. The searches covered the full range of publication years up to April 2013.

Identified studies were screened by title, abstract and full-text and considered for inclusion in the review if they were published in English; included a clearly defined sample of adults with mental health problems aged 18-65 (irrespective of the presence of other disabilities); and presented 'original' empirical data/research, including qualitative studies of service users' experiences of personal budgets. Studies were excluded if they were not available in English; included only people younger than 18 or older than 65 (as the use of personal budgets appears to be substantively different in these age groups and requires separate reviews); included only a sample of people with a disability where there was no evident mental health problem; focused only on person centred counselling or therapy (with no personal budget), or professional or organisational views; did not present separate results for people with a mental health problem; were opinion or comment pieces, or re-presented original research; or focused only on people's experiences of the processes involved in delivering personal budgets with no outcome data presented.

To check inter-rater reliability of the application of the inclusion/exclusion criteria, the titles and abstracts of 20 randomly selected articles were double-screened by another researcher, as recommended by SCIE (Rutter et al., 2010). Additionally, the full text of ten studies was reviewed by three additional researchers. Discrepancies which arose were discussed and referred to the principal investigator and the EAG, and the

selection criteria were amended accordingly. Full-text studies which were not available to the researchers were obtained directly from the authors.

Data were extracted from the included studies using a standardised tool adapted from the EPPI-Centre Keywording Sheet (EPPI-Centre, 2002) and the SCIE Data Extraction Tool (Rutter et al., 2010). This tool facilitated the collection of details about the nature of the study, intervention and the outcomes. The tool also included a number of possible coding categories that was used to facilitate data analysis.

The quality of the included studies was appraised in order to assess the extent to which they had met the established norms for studies with those designs and reliably answered the question under investigation. Each tool included a number of domains which were considered to constitute a 'low', 'moderate' or 'high' risk of bias. There was also an overall risk of bias assigned to each study which comprised an average of the domain scores.

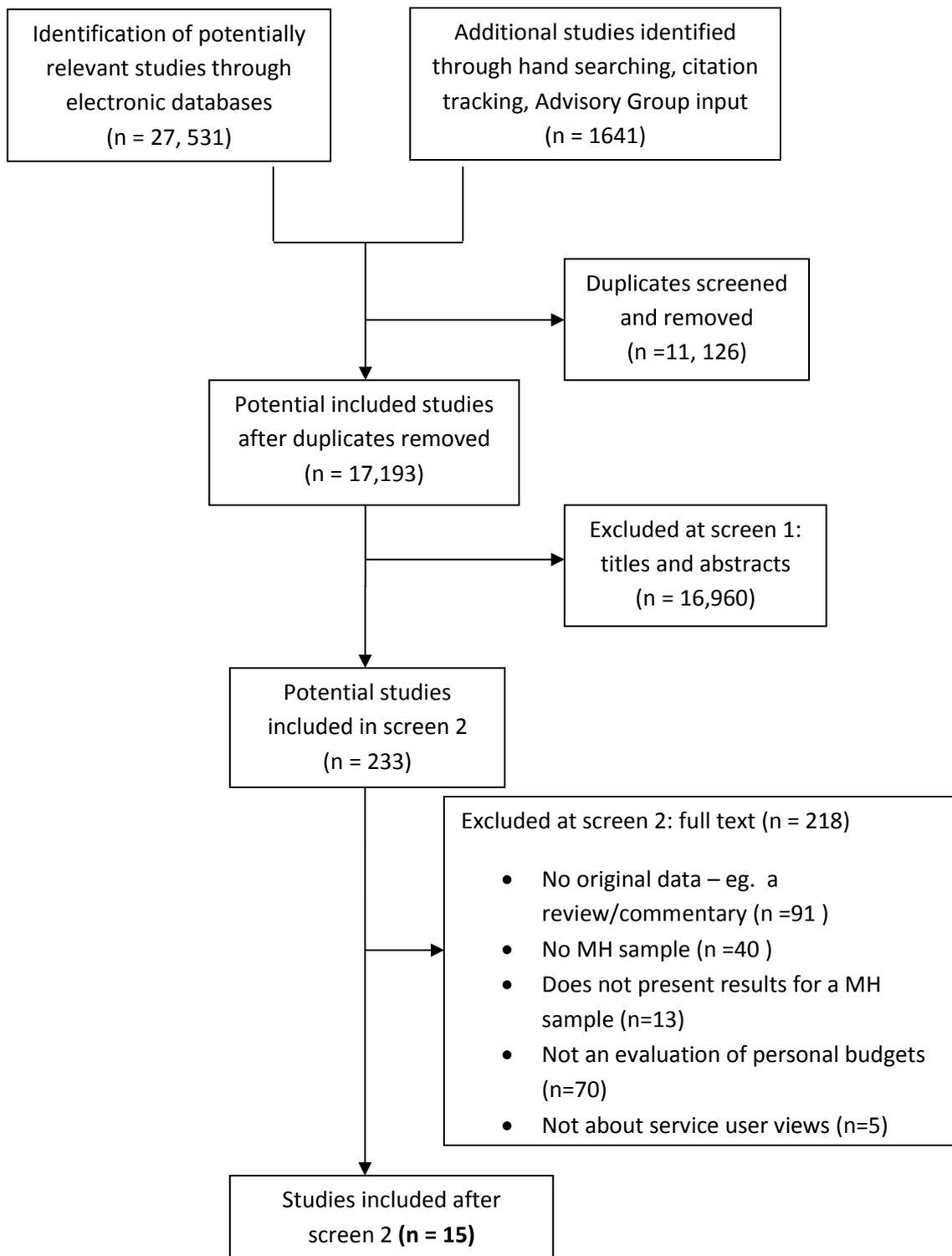
The Cochrane Collaborations's risk of bias tool (Higgins et al., 2011) was adapted for use in the assessment of the randomised controlled trials and quasi-experimental studies. The Critical Appraisal Skills Programme (CASP) appraisal tool (National Collaborating Centre for Methods and Tools, 2011) was used in an abbreviated form to assess the qualitative studies, and Webber's (2011) quality appraisal tool for cross-sectional surveys was also used. The latter tools were adapted to approximately map onto the categories of bias used in the Cochrane tool to allow for comparisons. Where studies used a mixed design, each part of the study was considered separately, such as the Personal Health Budgets evaluation (Davidson et al., 2012; Forder et al., 2012).

The variety of methodologies and analyses used in the studies eligible for review precluded the use of any meta-analysis (Harden & Thomas, 2005). Therefore, using the data extraction tool to form the basis of a narrative synthesis, findings were synthesised according to different outcome domains.

Results

15 studies met our inclusion criteria and the selection process is summarised in figure 1 below.

Figure 1: Application of selection criteria



Descriptions of the studies included in the review can be found in table 1 below. All studies were conducted in the UK or USA. Only two were RCTs, though an additional four used quasi-experimental methods. Only seven studies reported follow-up data. 1,135 people participated in 14 of the studies (range=2-412). The mean ages of samples ranged from 42–53 years and the proportion of people of black and minority ethnic (BME) origin ranged from 3%-50%. The proportion of females ranged from 26-70%. Participants were not defined by their sexual orientation. Studies evaluated individual budgets (n=2), recovery budgets (n=1), personal budgets (n=5), direct payments (n=1), personal health budgets (n=2) and 'cash and counselling' (n=4) as defined by their authors.

Table 1: Study descriptions

Study No.	Study, year (country)	Study Design	Sample Size	(1)Age (2)Gender (3)BME	Outcome measures	Control Group	Intervention	(1)Length of follow-up (2)Length of budget (3)Payment used (4)Items purchased
1	Glendinning et al, 2008 (UK)	RCT	n=131 Intervention (n=66) Control (n=65)	(1)Mean=49 (2)46% female (3)5% BME	ASCOT(Netten, Forder, & Shapiro, 2006); GHQ-12(Goldberg & Williams, 1988); Perceived QOL(Bowling, 1995); Self-rated health(based on Robine, Jagger, & Romieu, 2003); Whether views have changed on what could be achieved in life; Overall satisfaction with support and specific aspects of quality based on User Experience Survey(Jones, Netten, Francis, & Bebbington, 2007). Cost effectiveness measured with ASCOT and GHQ	Care as usual	Individual Budgets	(1)6 months (2)Unclear (3) 71% DP; 26% LA (4)65% leisure, 57% social care; 31% PA
2	Homer et al, 2008 (UK)	Qualitative	n=2	Not given	Study-specific semi-structured interview schedule.	None	Individual Budgets	(1)None (2-4)Unclear
3	Coyle, 2009 (UK)	Qualitative	n=7 n=4 at follow-up	(1&3)Not given (2)Female=2	Use of a 'narrative frame' which is not described in any detail.	None	Recovery Budgets	(1)7-8 months and 10-11 months (2&3)Unclear (4)Most spent on IT equip, Gym, driving lessons, bike, course, home improvements
4	Cheshire West & Chester Council, 2010 (UK)	Cross-sectional survey	Total (n=203) mental health sample size not given	Not given	Study-specific questionnaire	None	Personal Budgets	(1)None (2)Unclear (3)MH and LD had money paid into other's a/c more than other groups (4)Unclear
5	Eost-Telling, 2010 (UK)	Qualitative	n=11	(1 & 3) Not given (2)Female=3	The narrative frame or interview schedule is not clear.	None	Personal Budgets	(1)None (2)Unclear (3)Unclear (4)Total sample leisure

								activities/PA, home improvements, gym
6	Hatton & Waters, 2011 (UK)	Cross-sectional survey	n=78	Not given	POET(Hatton&Waters, 2011)	None	Personal budgets	(1)None (2) 43% PB <1 yr, 34% 1-3 yrs, 22% >3 yrs (3)67% DP (4)Unclear
7	Lawson et al, 2010 (UK)	Cross-sectional survey	n=17	Not given	Short multiple-choice study-specific questionnaire	None	Personal Budgets	(1)None (2-4)Not clear
8	Rogers, 2009 (UK)	Qualitative	n=4 service users; n= 2 carers	(1&3)Not given (2)Female (n=3 service users, n=1 carer)	Semi-structured interview tool	None	Personal Budgets	(1)None (2 - 4)Unclear
9	Spandler & Vick, 2004 (UK)	Mixed: qualitative and cross-sectional survey	Qualitative (n=27); Questionnaire (n=16).	Not given	Semi-structured interview adapted from Witcher et al(2000)&Ridley and Jones(2002) Quality of life questionnaire informed by the Lancashire QoLP(Oliver, 1991).	None	Direct Payments	(1)None (2)Mean=8.5 months (3)All DPs (4)PAs, then leisure, education, domestic support, pooled budget for arts group
10	Forder et al, 2012 (UK)	Quasi-experimental controlled trial	N=412 Intervention (n=228); Control (n=184)	(1)Intervention mean=45, control mean=53 (2)49% female (3)10% BME in intervention group, 3% in control	ASCOT;GHQ-12;Perceived QoL;Self-rated health(based on Robine et al., 2003); Whether views have changed on what could be achieved in life; EQ-5D(Brooks, Rabin, & de Charro, 2003); Subjective well-being scale based on Dolan et al(2010)	Care as usual	Personal Health Budgets	(1)12 months (2)Unclear (3)27%DP, notional 8%, 3 rd party – 63% (4)Social care, well-being, other health and therapy & nursing
11	Davidson et al, 2012 (UK)	Qualitative	n=9 at 3 months, n=8 at 9	Not given	Semi-structured topic guide	None	Personal Health Budgets	(1)3&9 months (2-4)Unclear
12	Shen et al, 2008 (USA)	RCT	n=228 Intervention (n=109) Control (n=119)	(1)70% aged 40-64 (2)70% female (3)50% White	No specific outcome measures were used, though the following outcomes were documented: the use of personal care services; perceptions of caregivers' reliability and attitude; satisfaction with overall care arrangements; perceived unmet needs; adverse events; and satisfaction with life.	Care as usual	Cash and Counseling	(1)9 months (2)Unclear (3)Via fiscal intermediary (4)Only can be spent on personal assistance

13	Teague & Boaz, 2003 (USA)	Quasi-Experimental – with control	n=21 Intervention (n=13) Control (n=8)	Not given	Structured interviews, questions taken from the Experiences of Care and Health Outcomes survey(Eisen et al., 1999), Working Alliance Inventory(Horvath & Greenberg, 1989), and others on service availability and use; perceptions of self-directed care; recovery goals; and outcomes.	Those who began the enrolment process but later declined	Based on Cash and Counseling	(1)None (2)Unclear (3)Fiscal intermediary (4)Mental health, physical health, housing, education/employment, enhancements (eg food, clothes, PA)
14	Cook et al, 2008 (USA)	Quasi-experimental (pre-post-design)	n=106	(1)Mean=42.4 (2)61% female (3)38% BME	Client outcome data compiled by the state mental health authority and GAF(Endicott, Spitzer, Fleiss, & Cohen, 1976)	None	Based on Cash and Counseling	(1)1 year (2)10.5 months (3)Fiscal intermediary (4)Traditional clinical services, clothes, food, non-traditional wellbeing services, uncovered medical expenses
15	Spaulding-Givens, 2011 (USA)	Quasi-experimental (no control)	n=80	(1)Mean=51.4 ; (2)61% female (3)24% BME	Progress towards goal attainment; no of days in community in past 30 days; no of days worked in last 30 days, and income earned from that work.	None	Based on Cash and Counseling	(1)1 year (2)4.1 years (3)Fiscal intermediary (4)Transportation, housing/rent, utilities, dentist, medication, counselling, computers, clothing and food

Key to abbreviations used in table:

BME=Black and minority ethnicity; DP=Direct payment; LD=Learning disability; MH=Mental health; LA=Local Authority; PA=Personal assistant; PHB=Personal health budget

None of the studies was considered to have a low risk of bias, with seven appraised as having a high risk of bias. A common limitation was a relatively small sample size, which impacted on analysis. Recruitment bias was evident in ten studies. The comparability of interventions in the multi-site studies (nos.1,2,6,9,10,11– see table 1) was made problematic by the different implementation of funding mechanisms at various stages of each study. None of the studies with quantitative data contained fully validated measures (for example, a perceived quality of life measure (Bowling, 1995) used in both Glendinning et al (2008) and Forder et al (2012) had not been validated for use with people with mental health problems) and none of the qualitative studies reflected on the impact that the researchers' position potentially had on data collection or analysis. Finally, detail about analysis was generally lacking. The results of the studies are summarised in table 2.

Table 2: Study findings

Study, year (country)	Main outcome / Summary of findings	Limitations	OVERALL RISK OF BIAS
INDIVIDUAL BUDGETS			
Glendinning et al, 2008 (UK)	Intervention group reported significantly higher perceived quality of life (p<0.05) IBs appear more cost-effective	Relatively small sample; a number did not have budgets in place; significant over-representation of DP users; QoL measure not validated for MH; no benchmark nor acceptability curves for cost-effectiveness analysis; IBs implemented differently across sites;	MODERATE
Homer et al, 2008 (UK, Scot)	Budgets enabled both participants to live a fuller life than otherwise	Very small sample, sampling strategy unclear; only included people in 'critical need'; unclear method of analysis; budgets implemented differently in each area; .	HIGH
RECOVERY BUDGETS			
Coyle 2009, 2011 (UK)	Narratives before receiving budget were 'regressive', in contrast with 'progressive' post-budget narratives. Holding budget described as "entirely beneficial" and was key to success. Hope and recovery were core narratives.	No description of sampling method, narrative frame or researcher/interviewers' stance; few negative/ambivalent themes; some of the items procured could have been obtained through other existing means;	MODERATE
PERSONAL BUDGETS			
Cheshire West & Chester Council, 2010 (UK)	Choice and control over life, and enagement in social and leisure opportunities had got worse, compared to other groups. Paid work had improved (of those in paid work) compared to other groups.	Sample and sampling strategy not described; no power calculations or discussion of response bias; no analysis described; no indication of significance or lack thereof of the results; only partial results presented.	HIGH
Eost-Telling, 2010 (UK)	Narratives reported were all positive. <i>Authority</i> - more in control, confident; <i>Direction</i> - a new direction/motivation; <i>Contribution</i> - contributing more to society; <i>Serendipity</i> - positive knock-on effects in other areas of their lives	Sample recruited from one person's case list; unclear about the interview frame, analysis, researcher's stance – interviewer was member of clinical team.; absence of negative or neutral narratives.	HIGH
Hatton & Waters, 2011 (UK)	<i>The following were reported as being better or a lot better:</i> being in control of support, being independent (74%); in control of life (73%); mental wellbeing (70%); feeling safe (68%); relationships with family (64%); physical health (62%); relationships with friends (53%). Majority endorsed 'no difference' for getting and keeping a job, volunteering and community health, and in choosing where/with whom to live.	Over-representation of DP users; measure used not validated; the analysis and the statistics for group comparisons not given; generally results varied greatly across sites.	HIGH
Lawson et al 2010 (UK)	People with MH problems and LD were more likely to report improvements in their health and taking an active part in the community.	Small sample; MH over-represented in sample relative to the population norm; no information on questionnaire, data collection, nor the statistical analysis.	HIGH
Rogers,	High level of satisfaction when support plans in place. For some, cycle of	The sample size is very small and only half had budgets; unclear what the	HIGH

2009 (UK)	admissions broken, one moved out of residential care. One felt a good service had been withdrawn, and another felt they had never had an effective service and still not. Generally, once package in place, less contact with staff.	analysis process was or impact of researchers on it; overall conclusion is not apparently linked to the analysis.	
DIRECT PAYMENTS			
Spandler & Vick, 2004 (UK)	<i>Quality of Life questionnaire</i> - positive impact on: self-worth (n=15); power and control (n=14); independence (n=13); mental health (n=13); contact with friends/relatives (n=9). Only negative was one persons' marital relationship. <i>Qualitative</i> – Increased autonomy, control, self-esteem; Increased social participation; Decrease in hospital admissions; Increased choice & control – some found it hard to make choices, experienced greater uncertainty.	Small sample sizes; stable/trustworthy/articulate more likely offered DPs; length of time people had DPs in place not considered long; sites pre-agreed what DPs could be used for; decisions service driven; variations in implementation across sites;	MODERATE
PERSONAL HEALTH BUDGETS			
Forder et al, 2012 (UK)	- Impact of receiving personal health budgets on outcomes: not significant - Cost analysis – ‘indirect costs’ were found to be significantly lower for PHB holders (at 5% level) - Cost-effectiveness – PHBs showed higher ASCOT –measured net benefits than conventional services (at 10% significance).	Relatively small sample size, low follow-up rate; PHB group less complex needs and were significantly younger than control; no cost-effectiveness threshold for ASCOT ;different sites implemented budgets differently;	MODERATE
Davidson et al, 2012 (UK)	Mostly improvements in well-being, stress, managing condition day-to-day, emergency service use and preparing for ill-health. A few negative responses also included mental health not improving as would like, no improvement, mental health had deteriorated.	Small sample, Recruitment bias as above; not all had PHB at 9 months; early stages report, may not be typical; no discussion of researcher impact on interview or analysis. Different sites implemented differently.	MODERATE
CASH AND COUNSELING-BASED			
Shen et al., (2008) USA	More likely to be very satisfied with overall care arrangements (p<0.001), and way life is being spent (p<0.05). Less need for routine health care at follow-up (p<0.01).	Number of people on budgets small; identifying sample from Medicaid claims problematic as people may not have made them in the previous year; unclear recruitment and outcome measures; proxies excluded.	MODERATE
Teague & Boaz, 2003 (USA)	15% reported very important services were not available to them, compared to 87% of control group (p<0.01), and were moving more quickly towards achieving goals (p=0.04). Also, increase in mental health (p=0.05) and independence (p=0.02).	Small sample; no well-defined comparison group; interview sample may not be representative; service participants seen as “higher functioning” than local MH population.	MODERATE
Cook at al, 2008b (USA)	More days in the community (than inpatient/forensic) compared to year before program (p<.01). Significantly higher GAF Scale scores in the year after joining the program (p<.001).	Methodology overall, outcome measures, follow-up periods for all measures, and whether all data has been reported are not clear.	HIGH
Spaulding-Givens, 2011 (USA)	Disability Index (p=0.02) was significant –the more severely rated this score, the lower the amount of money spent.	Sample under-powered; input errors and missing data reduced this further; service users not representative of wider mental health population.; one measure was phased out during study;	MODERATE

We identified and synthesised four outcome domains:

(i) Choice and control of care and support

Four studies (nos.5,6,9,13) reported an increase in the levels of perceived choice and control experienced by people with mental health problems, including feeling more in control of life and support (nos.5,6,9), and feeling more confident, independent and powerful (nos.5,6,9, 13). However, one study (no.4) found that relative to other social care groups, mental health service users felt less in control of their care and support when in receipt of a personal budget. Two studies found evidence of an increase in choice, including flexibility with how time and resources were spent (no.9) and availability of services to budget holders (no.13). However, the increase in choice was accompanied by feelings of uncertainty in some service users (no.9), particularly when they found it difficult to articulate their needs.

(ii) Impact on life

Personalised care improved quality of life/overall satisfaction (nos.1,2,8,12); community participation (nos.5,7,8); physical health (nos.6,7,12); goal achievement (no.13); and greater sense of hope and recovery (nos.3,9). Three studies found benefits for mental health (nos.6,9,13) and one had mixed findings (no.11). Two studies reported generally better relationships with people (nos.6,9), though this was not the experience of all participants (no.9). Finally, one study (no.4) found that a personal budget helped people to keep paid work relative to other groups, but another (no.6) showed a large majority for whom it had no impact on employment.

(iii) Service Use

No study reported an increase in the use of inpatient services. As expected, five studies (nos.8,9,10,11,14) reported a decrease in community mental health service use.

(iv) Economic evaluations

Only two of the studies (nos.1,10) reported cost-effectiveness analysis. One found that personal health budgets were cost-effective (no.10), and the other that individual budgets appeared to be cost-neutral (no.1).

Discussion

This review provides some evidence that personal budgets can have positive outcomes for people with mental health problems, but a large number of methodological shortcomings limit the extent to which these findings can be interpreted. Further limits of interpretation come from the different payment and support mechanisms in the studies included in the review, and the different contexts in which they are applied.

The quality of the studies included in this review was moderate at best, with seven low quality studies, which is rather worrying given the significant investment in research and evaluation on personal budgets over the last ten years. Many personal budget evaluations had a high risk of bias, including those by the organisation charged with the delivery of self-directed support in the UK. The mental health sample within large studies included in this review was quite small, which impacted on the size of effect needed to demonstrate statistical significance, or artificially magnified others. Recruitment bias in these studies suggests that some of the participants were less 'complex', which causes further extrapolation problems. Also, the longest follow-up period in any of the studies was one year which, with difficulties in setting up personal budgets, led to many participants not being in receipt of their budgets at follow-up. Within some studies the funding mechanisms were deployed differently between sites. Outcome measures differed in their validity and reliability, making it difficult to compare studies and reach conclusions. Also, outcomes for people of BME origin, or lesbian and gay people, are largely unknown and deserve further exploration.

Our review screened over 17,000 studies against our inclusion criteria making it possible that potentially relevant studies were inadvertently excluded. US evaluations of brokerage were often unclear about funding mechanisms so it is possible that some which had personalised funding, but did not mention it, were screened out. Further, it was difficult to distinguish between process and outcomes in some studies. Evaluations of experiences of self-directed support, for example, were not included unless they referred to outcomes for personal budget recipients.

To the best of our knowledge, this is the only systematic review of the international literature on the effectiveness of personal budgets for people with mental health problems. It has found generally positive outcomes for mental health service users in terms of choice and control, impact on quality of life, service use, and cost-effectiveness. However, methodological limitations make these findings rather unreliable and insufficient to inform policy and practice. There is a need for large high quality experimental studies in this key policy area to inform personal budget policy and practice with people with mental health problems.

References

Alakeson, V. (2010). *Issues in International Health Policy: International Developments in Self-Directed Care*. New York: The Commonwealth Fund.

Audit Commission. (2010). *Financial Management of Personal Budgets: Challenges and Opportunities for Councils*. London: Audit Commission.

Bodenheimer, T. (2003). Interventions to improve chronic illness care: evaluating their effectiveness. *Disease Management*, 6(2), 63-71.

Bowling, A. (1995). *Measuring Disease*. Buckingham: Open University Press.

- Brooks, R., Rabin, R., & de Charro, F. (2003). *The Measurement and Valuation of Health Status Using EQ-5D: A European Perspective: Evidence from the EuroQol BIO MED Research Programme*. Rotterdam: Kluwer Academic Publishers.
- Carr, S. (2010). *SCIE Report 36: Enabling Risk, Ensuring Safety: Personal Budgets and Self-Directed Support*. London: Social Care Institute for Excellence.
- Carr, S. (2011). Enabling risk and ensuring safety: Self-directed support and personal budgets. *Journal of Adult Protection*, 13(3), 122-136.
- Carr, S., & Robbins, D. (2009). *Research Briefing 20: The Implementation of Individual Budget Schemes in Adult Social Care*. London: Social Care Institute for Excellence.
- Cheshire West & Chester Council. (2010). *Findings from the Personal Budgets Survey*. Cheshire: Cheshire West & Chester Council.
- Cook, J. A., Russell, C., Grey, D. D., & Jonikas, J. A. (2008). Economic grand rounds: A self-directed care model for mental health recovery. *Psychiatr Services*, 59(6), 600-602.
- Copeland, M. E. (2002). Wellness recovery action plan: a system for monitoring, reducing and eliminating uncomfortable or dangerous physical symptoms and emotional feelings. *Occupational Therapy in Mental Health*, 17(3-4), 127-150.
- Coyle, D. (2009). *Recovery Budgets in a Mental Health Service: Evaluating Recovery Budgets for People Accessing an Early Intervention Service and the Impact of Working with Self Directed Services on the Team Members within a North West of England NHS Trust*. Chester: University of Chester.
- Davey, V., Fernández, J. L., Knapp, M., Vick, N., Jolly, D., Swift, P., . . . Priestle, M. (2007). *Direct Payments: A National Survey of Direct Payments Policy and Practice*. London: PSSRU, London School of Economics.

Davidson, J., Baxter, K., Glendinning, C., Jones, K., Forder, J., Caiels, J., . . . King, D. (2012). Personal Health Budgets: Experiences and Outcomes for Budget Holders at Nine Months - Fifth Interim Report. Canterbury: Personal Social Services Research Unit.

Department of Health. (2005). Independence, Wellbeing and Choice: Our Vision for the Future of Social Care for Adults in England. London: Department of Health.

Department of Health. (2007). Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care. London: Department of Health.

Department of Health. (2009). Personal Health Budgets: First Steps. London: Department of Health.

Dolan, P., Layard, R., & Metcalfe, R. (2010). Measuring Subjective Wellbeing for Public Policy: Recommendations on Measures. London: LSE.

Eisen, S. V., Shaul, J. A., Clarridge, B., Nelson, D., Spink, J., & Cleary, P. D. (1999). Development of a Consumer Survey for Behavioral Health Services. *Psychiatric Services*, 50(6), 93-98.

Endicott, J., Spitzer, R. L., Fleiss, J. L., & Cohen, J. (1976). The Global Assessment Scale: a procedure for measuring overall severity of psychiatric disturbance. *Archives of General Psychiatry*, 33, 766-771.

Eost-Telling, C. (2010). Stockport Self Directed Support Pilot in Mental Health: Final Report of the Evaluation of the Self Directed Support Pilot. Chester: University of Chester.

EPPI-Centre. (2002). Core Keywording Strategy: Data Collection for a Register of Educational Research. Version 0.9.7. London: EPPI-Centre, Social Science Research Unit.

Forder, J., Karen Jones, Glendinning, C., Caiels, J., Welch, E., Baxter, K., . . . Dolan, P. (2012). Evaluation of the personal health budget pilot programme. University of Kent: Personal Social Services Research Unit.

- Glendinning, C., Challis, D., Fernández, J.-L., Jacobs, S., Jones, K., Knapp, M., . . . Wilberforce, M. (2008). *Evaluation of the Individual Budgets Pilot Programme: Final Report*. York: Social Policy Research Unit, University of York.
- Goldberg, D., & Williams, P. (1988). *A user's guide to the general health questionnaire*. Windsor: NFER-Nelson.
- Gough, D., Oliver, S., & Thomas, J. (2012). *An Introduction to Systematic Reviews*. London: Sage.
- Harden, A., & Thomas, J. (2005). Methodological Issues in Combining Diverse Study Types in Systematic Reviews. *International Journal of Social Research Methodology*, 8(3), 257-271.
- Hatton, C., & Waters, J. (2011). *The National Personal Budget Survey*. Lancaster: In Control / Lancaster University.
- Health and Social Care Information Centre. (2013). Measures from the Adult Social Care Outcomes Framework - England, 2011-12 - Final. Accessed from: <http://www.hscic.gov.uk/catalogue/PUB10284> 14th August 2013: Health and Social Care Information Centre.
- Her Majesty's Government. (2011). *No Health Without Mental Health: A Cross-Government Mental Health Outcomes Strategy for People of All Ages*. London: Department of Health.
- Higgins, J. P. T., Altman, D. G., Gøtzsche, P. C., Jüni, P., Moher, D., Oxman, A. D., . . . Sterne, J. A. C. (2011). The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *British Medical Journal*, 343(7829), 889-893.
- Homer, T., & Gilder, P. (2008). *A Review of Self-Directed Support in Scotland*. Edinburgh: Scottish Government Social Research.

- Horvath, A. O., & Greenberg, L. S. (1989). Development and validation of the Working Alliance Inventory. *Journal of Counseling Psychology, 36*(2), 223-233.
- Jacobs, S., Abell, J., Stevens, M., Wilberforce, M., Challis, D., Manthorpe, J., . . . Netten, A. (2013). The personalization of care services and the early impact on staff activity patterns. *Journal of Social Work, 13*(2), 141-163.
- Jones, K., Netten, A., Francis, J., & Bebbington, A. (2007). Using older home care user experiences in performance monitoring. *Health and Social Care in the Community, 15*(4), 322-332.
- Larsen, J., Ainsworth, E., Harrop, C., Patterson, S., Hamilton, S., Szymczynska, P., . . . Pinfold, V. (2013). Implementing personalisation for people with mental health problems: A comparative case study of four local authorities in England. *Journal of Mental Health, 22*(2), 174-182.
- Lawson, S., Pearmain, G., & Waters, J. (2010). Finding our way: The story of self-directed support in Barnsley. West Midlands: In Control.
- National Collaborating Centre for Methods and Tools. (2011). *Critical appraisal tools to make sense of evidence*. Hamilton, ON: McMaster University.
- Netten, A., Forder, J., & Shapiro, J. (2006). Measuring Personal Social Services Outputs for National Accounts: Services for older people, Discussion Paper No. 2267/3. Canterbury: Personal Social Services Research Unit.
- Newbronner, L., Chamberlain, R., Bosanquet, K., Bartlett, C., Sass, B., & Glendinning, C. (2011). *SCIE Report 40: Keeping Personal Budgets Personal: Learning from the Experiences of Older People, People with Mental Health Problems and their Carers* London: Social Care Institute for Excellence.

- NHS Confederation. (2011). *Personal Health Budgets: The Views of Service Users and Carers*. London: NHS Confederation.
- Oliver, J. P. J. (1991). The social care directive: development of a quality of life profile for use in community services for the mentally ill. *Social Work and Social Sciences Review*, 3(1), 5-45.
- Riddell, S., Pearson, C., Jolly, D., Barnes, C., Priestley, M., & Mercer, G. (2005). The development of Direct Payments in the UK: implications for social justice. *Social Policy & Society*, 4(1), 75-85.
- Ridley, J., & Jones, L. (2002). "Direct what": A study of direct payments to mental health service users. Edinburgh: Scottish Executive Central Research Unit.
- Robine, J. M., Jagger, C., & Romieu, I. (2003). Selection of a Coherent Set of Health Indicators for the European Union. Phase II: Final Report. Montpellier: Euro-REVES.
- Rogers, L. (2009). *Self Directed Support For Mental Health Service Users In West Sussex*. West Sussex: West Sussex County Council.
- Rutter, D., Francis, J., Coren, E., & Fisher, M. (2010). *SCIE Systematic Research Reviews: Guidelines* (2nd ed.). London: Social Care Institute of Excellence.
- Schrank, B., Bird, V., Rudnick, A., & Slade, M. (2012). Determinants, self-management strategies and interventions for hope in people with mental disorders: Systematic search and narrative review. *Social Science & Medicine*, 74(4), 554-564.
- Shen, C., Smyer, M., Mahoney, K. J., Simon-Rusinowitz, L., Shinogle, J., Norstrand, J., . . . del Vecchio, P. (2008). Consumer-directed care for beneficiaries with mental illness: lessons from New Jersey's Cash and Counseling program. *Psychiatr Serv*, 59(11), 1299-1306.

- Slade, M. (2009). The contribution of mental health services to recovery. *Journal of Mental Health, 18*(5), 367 - 371.
- Slasberg, C., Beresford, P., & Schofield, P. (2012). How self directed support is failing to deliver personal budgets and personalisation. *Research, Policy and Planning, 29*(3), 161-177.
- Social Care Institute for Excellence. (2013). Co-production in social care: What it is and how to do it. Adult Services SCIE Guide 51. London: Social Care Institute for Excellence.
- Spandler, H., & Vick, N. (2004). Direct Payments, Independent Living and Mental Health: An Evaluation. London: Health and Social Care Advisory Service.
- Spaulding-Givens, J. (2011). Florida Self-Directed Care: An Exploratory Study of Participants' Characteristics, Goals, Service Utilization and Outcomes. Florida: Florida State University.
- Spicker, P. (2013). Personalisation Falls Short. *British Journal of Social Work, 43*(7), 1259-1275.
- Taylor, N. S. D. (2008). Obstacles and dilemmas in the delivery of direct payments to service users with poor mental health. *Practice: Social Work in Action, 20*(1), 43-55.
- Teague, G. B., & Boaz, T. L. (2003). Evaluation of the Adult Mental Health Self-Directed Care Project. Florida: Florida Department of Children and Families.
- The Health Foundation. (2010). Personal Health Budgets: Research Scan. London: The Health Foundation.
- Webber, M. (2011). *Evidence-Based Policy and Practice in Mental Health Social Work* (2nd ed.). Exeter: Learning Matters.
- Witcher, S., Stalker, K., Roadburg, M., & Jones, C. (2000). Direct Payments: The Impact on Choice and Control for Disabled People. Edinburgh: The Scottish Executive Central Research Unit.

