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Implementing and Delivering Personalised Budgets for Drug and Alcohol Users: A Narrative Systematic Review

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Conflict of Interest

None

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Abstract

Personalised budgets have historically been provided to groups of people with varying long-term health and social care needs. Since 2010, there has been increasing interest in providing personal budgets (PBs) to individuals with a history of drug and alcohol use in the United Kingdom, reflecting the policy and practice shift towards whole person recovery from substance use. However, information on implementing, delivering, and receiving such initiatives with this group is limited. This systematic review was conducted to identify and collate the existing experiences of providing personalised budgets to drug and alcohol users. Between March and April 2017, we searched six electronic and eleven grey literature databases for English language studies published between 1990 and April 2017 which described the implementation and delivery of personalised budget initiatives with drug and alcohol users. Search results (n = 6,749) were screened against inclusion and exclusion criteria; six records met the inclusion criteria. Across the studies, staff reported specific moral, ethical, and practical issues which affected the implementation and delivery of personalised budgets to drug and alcohol users. Staff working with drug and alcohol users with PBs reported greater job satisfaction due to having greater flexibility and autonomy but they had increased workloads and additional responsibilities beyond their remit and training. Drug and alcohol users' experiences of receiving personalised budgets included varying levels of awareness, knowledge and control of their budgets, and difficulties in understanding what the budgets could be used for. Nevertheless, personalised budgets had been used to purchase various services and items beyond traditional drug and alcohol treatment. Outcomes for drug and alcohol users included reduced drug use, improved relationships, improved mental and physical wellbeing, and better daily structure. Although the review suggests that providing personalised budgets to drug and alcohol users presents unique implementation and delivery challenges, these were not insurmountable.

Keywords: Personalisation, personalised budgets, personal budgets, personal health budgets, substance use, implementation, narrative systematic review

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What is known about this topic

1. Personal budgets (PBs) are provided to individuals with complex health and social care needs to tailor care to best meet their needs.
2. Staff have identified challenges of implementing and delivering PB initiatives; experiences of individuals receiving PBs vary.
3. Providing PBs to drug and alcohol users has gathered increasing attention over recent years.

What this paper adds

1. This is the first known narrative systematic review of PBs for drug and alcohol users.
2. The review identifies that staff and services face specific moral, ethical and practical challenges when implementing and delivering PB initiatives for drug and alcohol users.
3. PB implementation and delivery issues influence how drug and alcohol users experience PBs.

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Introduction

In the United Kingdom (UK), a personal budget (PB) is an allocation of funding given to an individual to spend on support and services to meet their social needs (Alakeson, 2008). Personalised budgets first appeared as Direct Payments (DPs) under the Community Care Act 1996 (HM Government, 1996), which granted local authorities the power to allocate payments to people with a physical disability in lieu of services (Forder et al., 2012; HM Government, 1996). This legislation was designed to promote independent living for people with enduring disabilities and to challenge the status quo of professionally-led decision making (Prime Minister's Strategy Unit, 2005; Social Care Institute for Excellence, 2010). In 2001, after the implementation of the Health and Social Care Act (Department of Health, 2001), local authorities offered DPs to those eligible for social care services and to users of community care services who were able to manage them, with or without assistance (Department of Health, 2002). DP provision was later extended to individuals subject to mental health legislation (Gheera, 2012).

As the political landscape changed, personalised budgets gained traction in the health and social care arenas for individuals with ongoing health and wellbeing needs (Alakeson, 2010; Kmietowicz, 2009). PBs and personal health budgets (PHBs) addressed some of limitations and complex administrative and legal drawbacks associated with DPs (NHS, 2015) (Text box 1). Such initiatives urged services to become more responsive to individuals' needs and encouraged patients to manage their own healthcare (HM Government, 2010a, 2011).

[INSERT TEXT BOX 1 HERE]

The foundations of personalised budgets originate from the personalisation movement of the 1980s in the United States (US) which promoted person-centred care and individual decision-making (Glasby & Littlechild, 2009). This was accompanied by a need for more self-directed support and individualised

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funding for people with personalised care plans (Alakeson, 2007; Robbins, 2006). Since then, several countries in North America, Australasia, Scandinavia, and Western Europe have introduced personal budgets (Gadsby, 2013; The Health Foundation, 2010). The Health Foundation's international review (2010) acknowledged that despite variation between personal health and social care budget initiatives and the policy and cultural contexts within which they operate, the main aim of these schemes is to reduce health and social care costs.

Driven by giving people with unmet health and social needs more choice to make decisions about which services would best meet their needs (Alakeson, 2014; Brewis & Fitzgerald, 2010), personalisation has become a central theme of health and social care policy, most prominently in the US and UK (Cabinet Office, 2007; Darzi, 2008; Gadsby, 2013; The Health Foundation, 2011). Reflecting the policy shift, person-centred care is a central feature of the US Patient Protection and Affordable Care Act of 2010, and the UK Care Act of 2014 (Department of Health, 2014).

Dependence on alcohol and/or other drugs is a chronic condition encompassing both health and social factors (McLellan et al., 2000). Consequently, drug and alcohol users often engage with a range of health and social care services (Leadbeater, Bartlett, & Gallagher, 2008). With growing recognition that substance use may cause substantial health, social, and economic harm to individuals and society, policy and practice began to consider how to reduce these harms and help individuals to attain social and personal resources, reduce substance use, and develop recovery capital (Cornes et al., 2015; HM Government, 2010b; HM Government, 2017; Leadbeater, Bartlett & Gallagher, 2008; Public Health England, 2014; Public Health England, 2017; Roberts & Bell, 2013). Personalised working and person-centred approaches therefore received increasing attention as ways to support substance users' range of healthcare, housing, education, employment, and personal finance needs to encourage reintegration into society (Cornes et al., 2015; NICE, 2012).

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The use of personalised budgets to help substance users identify, shape, and meet their own recovery-oriented goals also aligns with the policy and practice shift from short-term pharmacological treatment (HM Government, 2010b; HM Government 2017; National Treatment Agency, 2010; Public Health England, 2014). Substance users may benefit from personalised budgets, especially those for whom traditional therapeutic options have been unsuccessful and who have disengaged from treatment services. This is because personal budgets are not restricted to fixed commissioned medical services or approved treatments, but they can be used to access health, social, and other services outside traditional substance use services (NICE, 2016). For example, PBs can be used towards education, training, leisure, and recreation activities to temper substance use, encourage personal development and foster social inclusion. Recipients are encouraged to develop personalised care plans which account for their needs, consider how risks can be managed, and identify how their personal budget may best meet their needs. In so doing, PBs aim to provide individuals with greater power and choice over traditional treatment routes and encourage greater control (Hamilton et al., 2015). However, as with all PBs, critics worry that budgets may be spent on care that has little or no effectiveness and raise concerns if PBs are exhausted without needs being met (Alakeson et al., 2016).

Personal budgets have been implemented differently in different countries, with different population groups (Gadsby, 2013; The Health Foundation, 2010). Nevertheless, evaluations have consistently identified issues linked to implementing and delivering these initiatives across populations in the UK (Forder et al., 2012; Glendenning et al., 2008; Jones et al., 2010), the US (Brown et al., 2007), the Netherlands (van Ginneken, Groenewegen & McKee, 2012), and Australia (Gordon et al., 2012). For example, in the UK Jones et al. (2010) identified PHB implementation challenges which included: i) difficulties managing additional resources, including the need to identify costs of services and support people through the care planning process; ii) issues with managing direct payments to limit risks to PHB holders; iii) uncertainty surrounding the boundaries of what could be covered by budgets; iv) difficulties encouraging services to see individuals as the best judges of what services they need; v)

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problems engaging middle managers and; vi) struggling to promote choice and control in the absence of a clear and developed market. Similar implementation challenges have been identified in mental health (Webber et al., 2014) and dementia patients (Goodchild, 2011). Reported challenges have also included difficulties in integrating funding streams and a lack of staff training and guidance, resulting in staff uncertainty when working with budget holders and delays in implementation and delivery (Jones et al., 2010). Understanding how individual budgets have been calculated and deciding how to use them have been challenges reported by IB recipients (Glendenning et al., 2008).

Even though an international review found that PBs helped people to feel more empowered and confident about their care, it highlighted that little high-quality, cross-sectional research has been conducted into personal budgets and identified gaps around the impacts of personal budgets on health outcomes and cost effectiveness (The Health Foundation, 2010). Indeed, in the UK outcomes associated with PBs and PHBs are mixed (National Audit Office, 2016). The *In Control* evaluation conducted across six local authorities in England, found that PBs helped recipients with learning disabilities to gain control over the type of support the accessed, improved self-determination, increased access to a wider range of support, improved their financial and home situation and increased participation in the community (Hatton et al., 2008). An evaluation of the impact of PBs on people with mental health problems, people with physical and sensory impairment and older people, showed that PBs increased participation in society, increased the level of control in their lives and led to a greater sense of personal dignity (Hatton et al., 2008). Furthermore, those who had used PBs for longer periods reported improvements in general health and well-being and greater economic stability (Tyson et al., 2010). Evaluations have also reported improvements in quality of life across a range of groups (Hatton et al., 2008; Tyson et al., 2010), including in the care-related quality of life (measured by the Adult Social Care Outcomes Toolkit ASCOT) and psychological well-being (measured by the General Health Questionnaire GHQ-12) in the national PHB pilot evaluation (Forder et al., 2012). More positive effects on outcome indicators were identified when pilots explicitly

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informed people the value of their budget, were flexible in what could be purchased, and when recipients could choose how to manage the budget (Forder et al., 2012; Jones et al., 2010).

The positive changes identified in the PHB evaluation however did not have a significant impact on health status, mortality rates or health-related quality of life (measured by the EQ-5D) or the reported use of informal care (Forder et al., 2012). Furthermore, some PB recipients reported limited health improvements (people with long-term disabilities), increased psychological distress from managing a PB (particularly older people) and considerable variation in the quality and availability of care (Alakeson, 2010; Benjamin, Mattjias, & Franke, 2000). Reported problems also arose around the lack of information those with PHBs received, frustration over the 'postcode lottery' of services available in some areas compared to others, and uncertainty if recipients did not know the value of their budgets (Davidson et al., 2013).

Although initiatives have researched the provision of personalised budgets to people with a history of drug and alcohol use (Daddow & Broome, 2010; Croydon DAAT, 2012; Welch et al., 2013), there is a recognised gap in the literature exploring the impact of a person-centred approach within the substance use care pathway (Welch et al., 2017). Reflecting the desire for improved evidence and understanding (National Audit Office, 2016), a recent report called for the experiences of different people including those who misuse substances to be considered when trying to understand the variation in provision, experience, and outcomes of personalised budgets on different groups (TLAP, 2017). This narrative systematic review aims to address these gaps by focussing on implementation and delivery of personalised budgets with drug and alcohol users, including any associated outcomes. For clarity, we use the term 'budget' to encompass any forms of personalised budgets (e.g. PBs, PHBs, self-direction) allocated without conditions to individual drug and/ or alcohol users to spend on their health and/ or social care, treatment and support needs as they see fit.

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Review aims

This narrative systematic review seeks to synthesise findings from the international personalisation and substance use literature to answer the following question: ***what is the existing evidence for providing personalised budgets to drug and alcohol users?*** Specifically, we wanted to identify:

i. Staff experiences of implementing and delivering personal budget initiatives with drug and alcohol users, and the associated outcomes.

ii. Drug and alcohol users' experiences of receiving personal budget initiatives, and the associated outcomes.

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Methods

Searching for studies

We used a rigorous and comprehensive search to identify studies for this systematic review (Centre for Reviews and Dissemination, 2001; Pope, Mays, & Popay, 2007). Between March and April 2017, we searched six electronic academic databases: CINAHL (start – April 21st 2017); EMBASE (1974 – week 16, 2017); Medline (1946 – April 2017 week 2); Medline ahead of publication (1946 – April 2017 week 2); PsycINFO (1806 – April 2017 week 2) and Web of Science (1900 – April 2017 week 2).

To be sensitive to database indexing, we devised a separate search string for each electronic database. The search strings included both subject headings and free text words (truncated where appropriate) encompassing both i) drug and alcohol substance use and ii) personalisation and personal budgets. To ensure the search retrieved relevant studies, all drug and alcohol substance use terms were exploded and were combined using 'OR' and all personalisation/personal budget terms were exploded and were combined using 'OR'. The drug and alcohol substance use terms were then combined with the personalisation and personal budget terms using 'AND' (Table 1).

[Insert Table 1 here]

We limited the searches to English language studies published between 1990 and April 2017 week 2. The results returned by each academic database are shown in Table 2. The results were downloaded into Endnote X8™ and duplicates (n = 1,928) were removed.

[Insert Table 2 here]

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To identify relevant studies not indexed in the electronic academic databases, we also searched the 'grey literature'. Using key words relating to drug and alcohol substance use and personal budgets, we searched OpenGrey, the Campbell Collaboration Library, Scopus, the British Library's Ethos theses portal, [institution removed for anonymity reasons] Pure portal, Worldcat, Healthcare Management Information Consortium (HMIC), Social Care Online, the Social Research Network, National Institute for Health and Care Excellence (NICE) Evidence Search, and the TRIP database. Duplicate records (n=6) were removed by cross checking.

Selecting studies

Across the academic databases and grey literature, a total of 6,749 records were identified. After removing duplicate records, both lead authors simultaneously screened the results by reading every title and abstract/ executive summary to identify eligible studies. As existing studies have reviewed the literature on the provision of budgets to specific populations including people with disabilities or mental health issues (Carter Anand et al., 2012; Fleming et al., 2016; Webber et al., 2014), we focussed the review to capture studies concentrating on substance use. Thus, studies were included for full review if they: i) reported empirical data regarding staff experiences of implementing and delivering personal budget initiatives with drug and alcohol users and/or drug and alcohol users' experiences of receiving personal budget initiatives; ii) were published in the English language and; iii) were published since 1990. To identify as many studies as possible, the inclusion criteria did not specify that studies had to be conducted in any setting or country and no age parameters were prescribed. Studies were excluded if they were: i) not based on empirical research (e.g. editorials, letters and literature reviews); ii) not specific to personal budget initiatives with drug and/ or alcohol users (e.g. if they involved a conditional element or if they did not differentiate between the findings for drug and alcohol users); ii) not in English or; iv) published before 1990. In line with the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) (Moher et al., 2009), Figure 1 details the records retrieved and reviewed at each stage.

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[Insert Figure 1 here]

The lead authors read the records that met the inclusion criteria. They noted the study aim, methods, participants, and findings on a data extraction sheet and hand searched the reference lists for any additional studies. The quality of the studies were assessed using the Critical Appraisal Skills Programme (CASP) (Public Health Resource Unit, 2006) (Table 3).

[Insert Table 3 here]

Characteristics of included studies

Six records from four studies/ programmes of work met the criteria for inclusion in the review. Two records report findings from the national evaluation of PHBs (Welch et al., 2013; Welch et al., 2017), and two report findings from an evaluation of Fulfilling Lives in Islington and Camden (FLIC) Programme for people with multiple and complex needs, which included substance users (Cornes, Whiteford, & Manthorpe, 2015; Whiteford, Cornes, & Williamson, 2016). Nevertheless, all records are separately included in the review as they focus on different aspects of the studies and/ or draw on different data. That is, both drug and alcohol users and staff are included in Welch et al., 2013; whereas Welch et al., 2017 centres on the views and experiences of staff. Similarly, Whiteford, Cornes, & Williamson was conducted in 2016 with different service users and staff as a follow-up to Cornes, Whiteford, & Manthorpe's 2015 study. Details of the included studies are provided in Table 4.

Five of the included studies report the findings of pilot initiatives in England (Callanan et al., 2012; Cornes, Whiteford, & Manthorpe, 2015; Welch et al., 2013; Welch et al., 2017; Whiteford, Cornes, & Williamson, 2016); the other was conducted with individuals from mental health self-direction programmes in the United States (Croft & Parish, 2016). Five of the studies report data from drug and/

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or alcohol users who received budgets, five include data from staff working with drug and/ or alcohol users who received personal budgets, and four included both drug and/ or alcohol users and staff. Two studies were published in peer reviewed journals (Croft & Parish, 2016; Welch et al., 2017); four are grey literature reports (Callanan et al., 2012; Cornes, Whiteford & Manthorpe, 2015; Welch et al., 2013; Whiteford, Cornes & Williamson, 2016).

The studies all report findings from empirical qualitative research. Only one study employed a mixed methods design, drawing on standardised questionnaires (Welch et al., 2013). Qualitative data from drug and alcohol users who had received budgets were collected using face-to-face interviews (Callanan et al., 2012; Cornes, Whiteford & Manthorpe, 2015; Croft & Parish, 2016; Whiteford, Cornes & Williamson, 2016) and telephone interviews (Cornes, Whiteford & Manthorpe, 2015; Welch et al., 2013). Staff data were collected using face-to-face interviews (Callanan et al., 2012; Whiteford, Cornes & Williamson, 2016), telephone interviews (Callanan et al., 2012; Cornes, Whiteford & Manthorpe, 2015; Welch et al., 2013; Welch et al., 2017; Whiteford, Cornes & Williamson, 2016) and focus groups (Callanan et al., 2012; Cornes, Whiteford & Manthorpe, 2015; Whiteford, Cornes & Williamson, 2016). The studies that included staff reported data from: stakeholders/commissioners (involved with setting up and implementing the budget programmes) (Callanan et al., 2012; Cornes, Whiteford & Manthorpe, 2015; Whiteford, Cornes & Williamson, 2016; Welch et al., 2013; Welch et al., 2017); frontline delivery staff (involved with the daily operation of budgets with drug and alcohol users) (Callanan et al., 2012; Cornes, Whiteford & Manthorpe, 2015; Welch et al., 2013; Welch et al., 2017; Whiteford, Cornes & Williamson, 2016); and senior managers (who supported the frontline workers) (Welch et al., 2013; Welch et al., 2017; Whiteford, Cornes & Williamson, 2016). Welch et al (2013; 2017) interviewed staff at two different time points.

[Insert Table 4 here]

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Findings

Below, we synthesise the findings from the included studies. Firstly, we present the findings regarding staff experiences of implementing and delivering personalised budget initiatives with drug and alcohol users, identifying between the different staff involved where possible.

Experiences of implementing and delivering personal budgets

The included studies identified that staff faced several moral, ethical and practical challenges implementing and delivering personal budget initiatives with drug and alcohol users (Callanan et al., 2012; Cornes, Whiteford & Manthorpe, 2015; Whiteford, Cornes & Williamson, 2016; Welch et al., 2013; Welch et al., 2017).

Moral and ethical issues

In Callanan et al (2012), some service staff and care co-ordinators were initially reluctant to refer drug and alcohol users for self-directed support (SDS) as they worried that they would not make appropriate decisions about how to use their budgets, questioned how suitable it was for drug and alcohol users to make such decisions, and raised concerns that users would request more expensive services than they required. Similarly, Link Workers in Whiteford, Cornes & Williamson (2016) and representatives across a range of organisations in Welch et al (2017) were concerned that drug and alcohol users may not use budgets appropriately, may sell budget purchases to fund substance use, and questioned what would happen in the event of relapse.

> *One of the worries that people have about the PHB was, well, what happens if people use all their money and then they relapse and go back using drugs again? Will we have to spend all the same money all over again?* (Health professional, Welch et al., 2017)

Practical issues

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Practical implementation and delivery issues raised by operational staff centred on who to target with PBs and when (Callanan et al., 2012; Welch et al., 2017). Callanan et al's study identified that staff were reluctant to use SDS with high need service users with drug and/or alcohol using histories as they perceived that the referral process and assessment would be more time consuming than traditional treatment and doubted that the kind of treatment needed would be available through SDS (Callanan et al., 2012). Similarly, operational staff worried that offering PHBs at crisis point could provoke anxiety for drug and alcohol users (Welch et al., 2017). Thus, staff in these two studies felt that budgets were most appropriate to support and sustain the recovery of lower need drug and alcohol users, who were abstinent or stable on substitute medication or nearing the end of treatment (Callanan et al., 2012; Welch et al., 2017).

In two studies (Callanan et al., 2012; Welch et al., 2017), a lack of guidelines on what budgets could fund contributed to delivery challenges for delivery staff and made it more difficult to support their clients. Discrepancies arose when organisational representatives perceived that drug and alcohol users' budget requests did not match their needs or included activities or services that went against evidence-based opinion (Welch et al., 2017).

> *People struggled with the notion of how it would actually work in substance misuse… how it was going to be seen to be used wisely, this money and what options people did have and how they were going to link those back to treatment needs.* (Delivery manager, Callanan et al., 2012)

Link Worker delivery staff in the Fulfilling Lives pilot appeared to have more autonomy to use service user's budgets to help with individual's immediate and practical needs (e.g. for housing and food) in times of crisis (Whiteford, Cornes & Williamson, 2016). Nevertheless, staff in both studies linked to

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this pilot (Cornes, Whiteford & Manthorpe, 2015; Whiteford, Cornes & Williamson, 2016) still alluded to discrepancies of opinion between one another about what budgets should be used for.

> *There probably are discrepancies throughout the team… Some people think `you know what, it's the service users' budget, if they want to do it let them do it' and some people think `well is that a good recovery focused idea'.* (Link Worker, Whiteford, Cornes & Williamson, 2016)

How to approve budget requests and provide budgets to drug and alcohol users also contributed to issues with delivering personal budgets in two included studies (Callanan et al., 2012; Whiteford, Cornes & Williamson, 2016). For example, staff worried when decisions regarding budget uses were made by managers without discussion with delivery staff who worked with individual drug and alcohol users (Callanan et al., 2012). Issues with formal procedures, such as uncertainty over who signed off budget requests and no time frame for decisions caused delays in providing budgets (Callanan et al., 2012). For managerial and delivery staff, issues including provider reluctance, administrative burdens, a lack of formal invoicing procedures, the complexity of brokering a range of personalised provision, and difficulties of reconfiguring provision to accommodate a different approach to delivery posed key challenges (Callanan et al., 2012; Welch et al., 2013). Such issues also contributed to delays in providing budgets (Callanan et al., 2012). However, delays in budget delivery was not an issue for FLIC staff where there were few procedural controls and formal sign off procedures to follow and where delivery staff could use service users' budgets as an 'enabling' or 'welfare' fund (Whiteford, Cornes & Williamson, 2016).

Staff worried that delays to access services through SDS/ PBs could disempower drug and alcohol users and jeopardise their engagement with treatment (Callanan et al., 2012). So, to avoid delays, managerial staff tried to streamline approval processes or members of staff purchased items for service users themselves and then invoiced the service (Callanan et al., 2012). In some studies, staff

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suggested that providing budgets through direct payments would give drug and alcohol users more flexibility and control over their budgets and would limit invoicing issues and delays (Callanan et al., 2012; Welch et al., 2013; Welch et al., 2017). Yet, concerns that giving greater control through direct payments might increase drug and alcohol users' vulnerability led project leads in Welch et al (2013 and 2017) to suggest ways to manage the potential risks of direct payments. Similarly, staff in Callanan et al (2012) suggested pre-paid cards as a potential alternative to direct payments. Reflecting this, disagreements amongst staff over who should control drug and alcohol user's budgets were suggested in the studies - some delivery staff wanted to give greater control to PB holders to increase empowerment and choice, whilst others wanted to maintain control of the budgets on behalf of drug and alcohol users, partly to limit service user vulnerability (Callanan et al., 2012; Welch et al., 2017; Whiteford, Cornes & Williamson, 2016).

Overcoming implementation and delivery challenges

Staff implementing and delivering personal budget initiatives valued training to help them promote self-directed support, refer service users, and consider what services would therapeutically benefit them beyond traditional drug treatment services (Callanan et al., 2012). Delivery staff anxieties about unwieldy assessments and delays in accessing provision were reduced once assessments were shortened and integrated into the comprehensive treatment assessment (Callanan et al., 2012). Likewise, purchasing procedures became clearer following the development and implementation of guidelines and protocols (Welch et al., 2017). One pilot site benefitted from employing a broker who assisted drug and alcohol users find the most appropriate provision for their needs, dealt with more administrative tasks, and invoiced for services, thereby freeing up staff to focus on their case work (Callanan et al., 2012). Finally, staff across all staff groups identified that reflective practice and strong, passionate leadership were important to manage and overcome operational challenges and enthuse people to provide budgets to drug and alcohol users (Whiteford, Cornes & Williamson, 2016; Welch et al., 2017).

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Outcomes for staff and treatment delivery

Operational and managerial staff perceived that providing budgets to drug and alcohol users influenced treatment provision. For staff in Callanan et al (2012) and Welch et al (2017) a benefit of introducing personal budgets was that existing services were more competitive and responsive to the needs of drug and alcohol users as they encouraged greater use of a wider range of services beyond traditional treatment services. They thought this led to existing services trying to improve the care and support they offered, to remain competitive and maintain their funding. Staff interviewed Welch et al (2017) felt that PBs appeared to change the dynamic of the relationship between commissioners and service providers by shifting power towards commissioners in the interests of drug and alcohol service users. Cost efficiencies were also reported as organisational representatives from Welch et al (2017) perceived that more could be done for service users within same budget limits. For example, services could reduce block contracts with providers and avoid referring to residential detox (Welch et al., 2017).

Both operational and managerial staff in Callanan et al (2012) and Welch et al (2017) reported that other benefits of providing personal budgets to drug and alcohol users included increased choice and responsibility over their treatment, more tailored treatment to meet their needs, and greater chance for recovery than through conventional services.

> *Rather than just banging them into rehab, now we're looking what package we could put around them in the community… Support plans are more holistic as they look at things outside of the medical.* (Operational staff, Welch et al., 2017)

Staff experiences of implementation and delivery across the included studies varied. Nevertheless, stakeholders and delivery staff perceived that working in collaboration with drug and alcohol users to

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identify their needs and plan support through personal budgets helped staff at all levels of seniority to respect and understand service users, and develop better, more equal, respectful, and trusting relationships with them (Cornes, Whiteford & Manthorpe, 2015; Welch et al., 2017; Whiteford, Cornes & Williamson, 2016).

For FLIC Link Workers, having greater autonomy to work with clients as they wished led to greater job satisfaction and a willingness to commit more time to them (Whiteford, Cornes & Williamson, 2016). However, delivery staff in Cornes, Whiteford & Manthorpe, (2015), Welch et al (2013) and Welch et al. (2017) also reported that involving individual drug and alcohol users in planning and decision making regarding their budgets and encouraging them to make their own choices took extra time, required staff to take on roles outside their remit, involved lots of paperwork, and increased staff workloads. Indeed, a Link Worker likened herself to an 'octopus' juggling multiple demands; a model of working which many believed would be unsustainable if the pilot was expanded into existing services (Cornes, Whiteford & Manthorpe, 2015).

Experiences of receiving budgets

The included studies identified that drug and alcohol users' experiences of receiving personal budget initiatives centred around their awareness of budgets, managing budgets, and using budgets.

Awareness of personal budgets

The included studies highlight differences in drug and alcohol users' knowledge about the value of their budgets. Most commonly, budget amounts were not disclosed to substance users (Callanan et al., 2012; Cornes, Whiteford & Manthorpe, 2015; Whiteford, Cornes & Williamson, 2016). Although substance users in the national PHB pilot were meant to know how much they had been allocated, interviews revealed that some did not, even up to nine months later (Welch et al., 2013). One PHB holder argued that if she had known the budget amount before the care planning process began, she

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would have made different choices (Welch et al., 2013). Nevertheless, when budget holders from the same study knew the value of their PHB, most were satisfied, commenting that the amount was *"very generous," "plenty"* for their needs (Welch et al., 2013).

Managing personal budgets

Various ways of managing budgets were identified across the studies. Two studies reported using a notional budget approach, where budget recipients identified services which were then purchased on their behalf (Callanan et al., 2012; Welch et al., 2013). The US study allowed budget recipients to manage their own budget, although it does not state how this was done (Croft & Parish, 2016). It is also unclear how budgets were managed in the Fulfilling Lives pilot (Cornes, Whiteford & Manthorpe, 2015; Whiteford, Cornes & Williamson, 2016). Although drug and alcohol users could have the option to receive budgets in the form of direct payments to make their own purchases, none were receptive to having this level of responsibility, so direct payments were not pursued (Callanan et al., 2012; Whiteford, Cornes & Williamson, 2016):

> *They don't give me cash or money, and I think they're right not to, I don't want them to.* (Whiteford, Cornes & Williamson, 2016)

Using personal budgets to access services and support

Across the studies, drug and alcohol users had varying levels of choice and control over how they used personal budgets. For example, drug and alcohol users in the FLIC pilot appeared to have little choice and control over their budgets as Link Workers used the budgets on their behalf (Whiteford, Cornes & Williamson, 2016). However, in the PHB pilot, recipients consistently felt that they had greater choice and control over the provision of care and treatment paid for by the PHB (Welch et al., 2013). One participant felt that self-direction was incompatible with the mutual support principles of Alcoholics Anonymous (Croft & Parish, 2016). Otherwise, service users in the PHB and SDS pilots and

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in the US self-direction programme liked taking responsibility for their own treatment and recovery and welcomed making decisions about what services and support to access to suit their individual needs and lifestyles (Callanan et al., 2012; Croft & Parish, 2016; Welch et al., 2013).

> *She* [care co-ordinator] *seems to let me direct it, just guides me in the right direction… but my say is the final say in things, and if I mess up, it's on my toes.* (Callanan et al., 2012)

All studies which included substance users reported how they had used their budgets (Callanan et al., 2012; Cornes, Whiteford & Manthorpe, 2015; Croft & Parish, 2016; Welch et al., 2013; Whiteford, Cornes & Williamson, 2016). PHB recipients had commonly purchased traditional residential or community detoxification services (Welch et al., 2013). More innovative PHB uses included driving lessons, alternative therapies (e.g. acupuncture and massage), leisure activities (e.g. gym classes, swimming, football and theatre tickets) and educational courses to improve life chances (Welch et al., 2013), resonating with purchases made in the SDS pilot (Callanan et al., 2012). Budgets had also been used for one-off purchases including clothing, passports, IT equipment, internet connections (Welch et al., 2013), diaries and mobile phone credit (Cornes, Whiteford & Manthorpe, 2015).

> *When I needed all black for college to do this course - you had to wear all black – they came with me to H&M and got my gear for me. You know it's little things like that… that can help.* (Whiteford, Cornes & Williamson, 2016)

Budgets had also paid for transport (Callanan et al., 2012; Cornes, Whiteford & Manthorpe, 2015; Croft & Parish, 2016; Welch et al., 2013) to attend mutual support meetings (Croft & Parish, 2016) and treatment services (Welch et al., 2013). Meanwhile, some of the UK studies which included service users also highlighted some drug and alcohol user uncertainty about how personal budgets could be used and what they could fund (Callanan et al., 2012; Welch et al., 2013). For example, budget

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recipients in the SDS pilots said that there was no definitive list of services that could be accessed using their budget (Callanan et al., 2012). Similarly, PHB holders wanted more information during care planning on how budgets could be and had been used to assist decision-making (Welch et al., 2013).

Furthermore, reflecting staff views, budget recipients in one of the included studies questioned when personal budgets should be provided (Welch et al., 2013). Recipients suggested that they would benefit most from the choices offered through the budgets after detoxification, rather than at crisis point (Welch et al., 2013). Indeed, PHB holders from this study commonly wanted post-detoxification after care to help prevent relapse, but they could not understand why after-care counselling could not be financed through their PHB (Welch et al., 2013).

Outcomes for drug and alcohol users

Drug and alcohol users believed that personal budgets helped to reduce their substance use/ prescribed medication (Callanan et al., 2012; Welch et al., 2013) and to promote and maintain recovery (Croft & Parish, 2016). They felt that choosing which services to access through self-directed support led to a greater chance of recovery, compared to those accessed through the mainstream treatment system (Callanan et al., 2012; Croft & Parish, 2016). Reflecting this, difference-in-difference analysis of the Alcohol Use Disorders Identification Test (AUDIT-C) data collected in the national PHB evaluation indicated that individuals in the PHB group had reduced excessive drinking at follow-up compared to the control group, although the sample size was too small to show a meaningful difference (Welch et al., 2013).

Drug and alcohol users reported that having choice and control over personal budgets improved and created more power-equal relationships with health professionals (Callanan et al., 2012; Welch et al., 2013). They also reported that using budgets to improve housing or to access leisure or education activities helped to provide routine and structure, reduce boredom, limit their time around other

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substance users and reduce their use (Callanan et al., 2012; Croft & Parish, 2016; Welch et al., 2013). Improvements in physical and mental health were attributed to using SDS to access gym passes, fitness equipment, and specific forms of counselling to tackle the underlying causes of their substance use (Callanan et al., 2012). Quantitative data analysis indicated greater improvements in care-related quality of life (ASCOT) and psychological well-being (GHQ12) for individuals who received PHBs compared to those who did not, although the difference was not statistically significant (Welch et al., 2013). Recipients noted benefits where SDS had funded travel to visit or undertake leisure activities with family:

> *It meant the world. It meant me not reoffending to get money so that I could do these things with my son.* (Callanan et al., 2012)

Finally, in two of the included studies, drug and alcohol users identified that they had experienced delays with budget purchases (Callanan et al., 2012; Welch et al., 2013). PHB holders believed that delays were due to bureaucracy, staff inexperience, or poor communication (Welch et al., 2013). Budget holders suggested that further information and more efficient implementation would have minimised delays and improved their experience of having a personal budget as delayed purchases made them feel frustrated, distressed, and anxious, especially if they were not kept informed (Callanan et al., 2012; Welch et al., 2013). Personal health budget recipients perceived that such emotions were not conducive to overcoming substance use and maintaining abstinence (Welch et al., 2013). Similarly, if contact between budget recipients and frontline staff reduced, patients reported feeling unsupported, vulnerable, and with unanswered questions about their budgets (Welch et al., 2013).

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Discussion

The aim of this narrative systematic review was to explore the existing international evidence for providing personalised budget initiatives to drug and alcohol users in the current climate of person-centred approaches and whole person recovery. The review focussed on staff experiences of implementing and delivering PBs and the experiences of drug and alcohol users receiving PBs. Using a systematic and transparent methodology to search the academic and grey literature, the review identified two academic, peer-reviewed publications and four grey literature reports that satisfied the review's inclusion criteria. Despite international interest in personalisation, all but one of the included studies were conducted in England.

Across the studies which included staff views on implementing and delivering PBs, two main issues appeared central. Firstly, staff raised moral and ethical issues which impeded the implementation and delivery of PBs, including beliefs that service users with a history of drug and/or alcohol use were unable to make appropriate decisions about how to use PBs. Secondly, staff reported practical implementation and delivery issues, including who to target with PBs and at what time point in their treatment; a lack of clear guidelines on what PBs could be used for; who should approve budget purchase requests; and delays in drug and alcohol users accessing PB purchases. Staff identified appropriate training on delivering PBs, simple and integrated assessment protocols, reflective practice, and a strong management team helped to alleviate some of these issues. This review found that staff delivering PBs had a greater appreciation of the needs of drug and alcohol users. Staff reported this led to more trusting, equal relationships with clients and increased autonomy to work flexibly with them, which enhanced their job satisfaction. However, staff also reported that working with individual drug and alcohol users with PBs could take longer due to increased coordination and administration tasks. In addition, staff sometimes developed extra responsibilities, beyond the original remit of their role, which resulted in increased workloads.

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The studies that explored drug and alcohol users' experiences of receiving personalised budgets found that recipients were often unaware of the value of their budget. Additionally, users appeared to have varying levels of control over their budgets which were typically managed notionally or controlled by keyworkers. Irrespectively, PBs were used in a variety of ways, including the purchase of items outside traditional drug/ alcohol treatment. Across the studies, drug and alcohol users reported that budgets helped to reduce substance use, improved their physical and mental health, improved their housing and social situations, and instilled structure and routine. Drug and alcohol users' experiences echoed staff concerns - they felt uncertain about what PBs could be used for (Forder et al., 2012), they did not always have enough information on how to use PBs, and they felt frustrated and ill-informed when budget purchases had been delayed.

From the limited, small scale studies included in this review, drug and alcohol users' experiences of receiving PBs seemed generally positive. That is, reflecting other literature conducted with other groups, individuals who directed their own care reported feeling more empowered and satisfied with their care than those who received conventional services (Alakeson, 2010; Glasby & Littlechild, 2009; Glendenning et al., 2008; Tyson et al., 2010).

This review lends weight to existing understandings of the implementation, delivery, and outcomes of budget initiatives in other groups, including older people, people with disabilities, and users of mental health services (Forder et al., 2012; Glendenning et al., 2008; Jones et al., 2011). Implementation issues included difficulties in understanding who should manage the PB, who was responsible for approving PB purchases, and how to minimise potential risks of using DPs. Delivery issues included staff reluctance to relinquish full control of PBs to recipients and a lack of understanding on how PBs

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could be a used, a problem exacerbated by the lack of clear purchasing guidelines (Jones et al., 2010; Jones et al., 2011). Moreover, there were delivery problems when PB purchases were delayed or took time to be approved and a lack of clarity over what boundaries should be in place to protect staff and PB recipients (Jones et al., 2010; Jones et al., 2011; Webber et al., 2014). Access to a broker sometimes offset these issues (Newbronner et al., 2011) – brokers supported individual recipients to manage their budget and untrained service staff benefitted from the broker's training and experience in PBs.

This review comprehensively collates studies on personalised budgets within substance use. A strength of this review is that we identified a range of primary data from academic articles and published evaluations and pooled the perspectives of individuals at the heart of personalised initiatives for drug and alcohol users, an area of increasing policy and practice interest (Daddow & Broome, 2010; Leadbeater, Bartlett & Gallagher, 2008; Cornes et al., 2015). From these studies, we have identified key similarities and differences in the contexts in which personalised budgets have been delivered and the mechanisms at play which may influence the experience of implementation, delivery, and outcomes for drug and alcohol users and staff. These findings provide key learning in relation to implementation and delivery and can be used as a basis to support future interest in how to implement and deliver PBs to drug and alcohol users.

However, this review has a number of shortcomings. Firstly, arguably reflecting the lack of research in this area, we only identified six records on providing personal budgets to drug and alcohol users. Secondly, as with other reviews (The Health Foundation, 2010; Gadsby, 2013), the potential for detailed comparisons is limited as the studies included in this review all adopted different PB models, offered different levels of budget over different lengths of time, afforded PB recipients varying levels of control, and varied in what PBs could be used for. Thirdly, as the studies chiefly favoured a qualitative methodology, there remains a dearth of detailed quantitative data analyses on the

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implementation and delivery of PBs for drug and alcohol users. More quantitative research would be needed to explore the statistical correlation and impact of PBs on drug and alcohol users. Finally, other than the study by Welch et al, all of the data was collected at a single point in time. Without longitudinal data, it is impossible to demonstrate how, and why, staff and drug and alcohol users' views and experiences of PBs may change over time.

Nevertheless, this review provides a starting point for further discussion about personalised budgets and will assist those considering personal budget implementation and delivery within substance use. For example, findings highlight that introducing PBs takes time to initiate and embed in substance use services. They suggest that staff across all grades need to receive adequate PB-specific information, education, and training *before* PB initiatives are introduced to minimise the experience of moral, ethical, and practical delivery issues. This points to the need for adequate investment to develop, train, and support substance use service staff working with PBs, an area which may have been overlooked. The review also identifies the benefit of strong leadership, collaborative working with brokers, alongside the need for clear guidance on the process of using and approving PBs before schemes 'go live' in services. With improved staff knowledge and awareness at the outset, it is hoped that substance users should receive clearer information and have increased understanding, knowledge, support, flexibility, and control to use PBs towards their health and social care needs.

To conclude, this systematic narrative review has identified specific implementation and delivery challenges which appeared to influence how staff and drug and alcohol users experience personalised budgets. Although PBs are intended to give recipients choice, control and the freedom to make decisions about the type of care receive, the initiatives described in the included studies did not remain completely true to the core principles of personalisation and PBs. Indeed, there was variation across the studies in how PBs were implemented and delivered – such as whether recipients knew the

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value of their budgets and the level of control that drug and alcohol users experienced. A finding of this review which contradicts the core principles of PBs however, is that drug and alcohol users did not appear to want more control of their budgets (Daddow & Broome, 2010). This was supported by staff who explained that implementing and delivering PBs with this group raised moral and ethical questions about how budgets would be used, resulting in users having little direct control of their PBs. On account of complex drug and alcohol histories and associated needs, implementing and delivering PBs for drug and alcohol users may thus be potentially more complex than for other groups. Consequently, the way PBs are delivered to drug and alcohol users will likely continue to raise questions around the level of control they have over personalised budgets.

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References

Alakeson, V. (2007). *The case for extending self-direction in the NHS*. London: Social Market Foundation.

Alakeson, V. (2008). Let patients control the purse strings. *British Medical Journal, 336*, 807-809.

Alakeson, V. (2010). International developments in self-directed care. *Issue brief (Commonwealth Fund), 78*, 1-11.

Alakeson, V. (2014). *Delivering personal health budgets: A guide to policy and practice*. London: Department of Health.

Alakeson, V., Boardman, J., Boland, B., Crimlisk, H., Harrison, C., Iliffe, S., Khan, M., O'Shea, R. & Patterson J. (2016). Debating personal health budgets. *British Journal of Psychiatry Bulletin*, 40, 34-37, doi: 10.1192/pb.bp.114.048827

Benjamin, A. E., Mattjias, R. E., & Franke, T. (2000). Comparing consumer-directed care and agency models for providing supportive services at home. *Health Services Research, 35*(1), 351-366.

Brewis, R., & Fitzgerald, J. (2010). *Citizenship in Health: Self-direction theory to practice*. West Midlands: Wytall

Brown, R., Carlson, B. L., Dale, S. B., Foster, L., Phillips, B. & Schore, J. (2007). *Cash and Counseling: improving the lives of Medicaid beneficiaries who need personal care or home- and community-based services. Final report*. Princeton, Mathematica Policy Research, Inc.

Cabinet Office. (2007). *HM Government Policy Review: Building on Progress: Public Services*. London: HM Government.

Callanan, M, Ranns, H, Turley, C, Barnard, M, Hussey, D, Chanfreu, J, & Bowles, R. (2012). *Drug System Change Pilots Evaluation: Final Report*. London: NatCen Social Research

Carter Anand, J., Davidson, G., MacDonald, G., Kelly, B., Clift-Mattews, V., Martin, A., & Rizzo, M. (2012). *The Transition to Personal Budgets for People with Disabilities: A Review of Practice in Specified Jurisdiction*s (pp. 49). Dublin.

Centre for Reviews and Dissemination. (2001). *Undertaking systematic reviews of research on effectiveness: CRD's guidance for those carrying out or commissioning reviews* York, UK: NHS Centre for Reviews and Dissemination.

Cornes, M., Mathie, H., Whiteford, M., Manthorpe, J., & Clark, M. (2015). The Care Act, Personalisation, and the New Eligibility Regulations. Retrieved from http://eprints.lse.ac.uk/61135/1/Clark_%20discussion_paper_about_the_future_of_care_author.pdf

Cornes, M, Whiteford, M, & Manthorpe, J. (2015). *Fulfilling Lives Islington and Camden: A Realist Review of Programme Theory*. London: Fulfilling Lives

Croft, B. & Parish, S. (2016). Participants' Assessment of the Impact of Behavioral Health Self-Direction on Recovery. *Community Mental Health Journal, 52*(7), 781-792.

Croydon Drug and Alcohol Action Team (2012). The Personalisation Programme PILOT - Substance misuse Croydon, Retrieved from: https://www.croydon.gov.uk/sites/default/files/articles/downloads/pilot.pdf

Daddow, R. & Broome, S. (2010). Whole Person Recovery: A user-centred systems approach to problem drug use. London: RSA

Darzi, A. (2008). *Our NHS, our future, NHS next stage review: final report*. London: Department of Health.

Davidson, J, Baxter, K, Glendenning, C, & Irvine, A (2013). Choosing health: qualitative evidence from the experiences of personal health budget holders. *Journal of Health Services Research and Policy, 18* (supplement 2): 50-58.

Department of Health. (2001). *Health and Social Care Act 2001*. London: Department of Health.

Department of Health. (2002). *Updated Drug Strategy 2002*. London: Department of Health.

Department of Health. (2014). *Care Act 2014*. London: Department of Health.

Fleming, P., Furlong, M., McGilloway, S., Keogh, F. & Hernon, M. (2016). Personal budgeting interventions to improve health and social care outcomes for people with a disability. The

Author accepted copy

Campbell Collaboration. Retrieved from: https://www.campbellcollaboration.org/library/personal-budgeting-outcomes-people-with-disability.html

Forder, J., Jones, K., Glendenning, C., Caiels, J., & Welch, E. (2012). *Evaluation of the personal health budget pilot programme*. London: Department of Health.

Gadsby, E. W. (2013). *Personal Budgets and Health: a review of the evidence*. London: PRUComm.

Gheera, M. (2012). *Direct payments and personal budgets for social care*. London: House of Commons Library.

Glasby, J., & Littlechild, R. (2009). *Direct payments and personal budgets: putting personalisation into practice*. Bristol: Policy Press.

Glendenning, C., Challis, D., Fernandez, J-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, N., Stevens, A., & Wilberforce, M. (2008). *Evaluation of the Individual Budgets Pilot Programme: Final Report*. York: Joseph Rowntree Foundation.

Goodchild, C. (2011). *Personal budgets for people with dementia: A report on challenges and solutions to implementation based on interviews with eight local authorities in England*. London: The Halcyon Project.

Gordon, C., Leigh, J., Kay, D., Humphries, S., Tee, K.-S., Winch, J. & Thorne, W. (2012). *Evaluation of the consumer-directed care initiative - Final report.* KPMG.

Hatton, C., Waters, J., Duffy, S., Senker, J., Crosby, N., Poll, C., Tyson, A., O'Brien, J. & Towell, D. (2008). *A report on In Control's Second Phase: Evaluation and Learning 2005-2007*. London: In Control Publications.

Hamilton, S., Manthorpe, J., Szymczynska, P., Clewett, N., Larsen, J., Pinfold, V., & Tew, J. (2015). Implementing personalisation in integreated mental health teams in England. J*ournal of Interprofessoinal Care,* 29(5), 488-493.

HM Government. (1996). Community Care (Direct Payments) Act 1996. Retrieved from: http://www.legislation.gov.uk/ukpga/1996/30/introduction

HM Government. (2010a). *Equity and excellence: liberating the NHS*. London: Department of Health

HM Government. (2010b). *Drug strategy 2010: Reducing demand, restricting supply, building recovery: Supporting people to live a drug free life*. London: Department of Health.

HM Government. (2011). *Government response to the NHS Future Forum report*. London: Department of Health.

HM Government. (2017). *2017 Drug Strategy*. London: HM Government.

Jones, K., Caiels, J., Forder, J., Windle, K., Welch, E., Dolan, P., Glendenning, C., & King, D. (2010). *Early experiences of implementing personal health budgets.* London: Personal Social Services Research Unit

Jones, K., Forder, J., Caiels, J., Welch, E., Windle, K., Davidson, J., Dolan, P., Glendenning, C., Irvine, A., & King, D. (2011). *The costs of implementing personal health budgets*. London: Personal Social Services Research Unit.

Kmietowicz, Z. (2009). Pilot projects for personal health budgets in England are announced. *British Medical Journal, 338*, b1996.

Leadbeater, C., Bartlett, J., & Gallagher, N. (2008). *Personal budgets and self-directed services mobilise the intelligence of thousands of people to get better outcomes for themselves and more value for public money*. London: Department of Health.

McLellan, A. T, Lewis, D. C, O'Brien, C. P., & Kleber, H. D. (2000). Drug dependence, A Chronic Medical Illness: Implications for Treatment, Insurance, and Outcomes Evaluation. *The Journal of the American Medical Association, 284*(13), 1689-1695.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. (2009). The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS One Medicine, 6*(7), e1000097.

National Institute for Health and Care Excellence (2012). *Drug Use Disorders QS23*. NICE, London.

National Institute for Health and Care Excellence (2016). *NICE guideline: Coexisting severe mental*

Author accepted copy

illness and substance misuse: community health and social care services. Retrieved from: https://www.nice.org.uk/guidance/ng58
National Audit Office (2016). *Personalised Commissioning in Adult Social Care*. National Audit Office. Retrieved from: https://www.nao.org.uk/wp-content/uploads/2016/03/Personalised-commissioning-in-adult-social-care-update.pdf
NHS. (2015). Frequently asked questions: Introducing personal health budgets beyond NHS Continuing Healthcare. Retrieved from: http://www.personalhealthbudgets.england.nhs.uk/_library/Resources/Personalhealthbudgets/2015/150303-FAQ_Introducing_PHB_beyond_CHC.pdf.
National Treatment Agency (2010). *Commissioning for Recovery. Drug Treatment, Reintegration and Recovery in the community and Prisons: A Guide for Drug Partnerships.* National Treatment Agency for Substance Misuse, London.
Newbronner, L., Chamberlain, R., Bosanquet, K., Bartllett, C., Sass, B., & Glendenning, C. (2011). *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.
Pope, C., Mays, N., & Popay, J. (2007). *Synthesising qualitative and quantitative health evidence: A guide to methods*. Maidenhead, UK: Open University Press.
Prime Minister's Strategy Unit. (2005). *Improving the Life Chances of Disabled People*. London: Retrieved from: https://core.ac.uk/download/pdf/4156824.pdf
Public Health England (2014). *Alcohol Treatment in England 2013-2014*. London: Public Health England.
Public Health England (2017). *An evidence review of the outcomes that can be expected of drug misuse treatment in England.* London: Crown copyright.
Public Health Resource Unit. (2006). Critical Appraisal Skills Programme. Retrieved from http://www.sph.nhs.uk/what-we-we-do/public-health-workforce/resources/critical-appraisals-skills-programme
Roberts, M. & Bell, A. (2013). Recovery in mental health and substance misuse services: a commentary on recent policy development in the United Kingdom. *Advances in Dual Diagnosis*, 6: 76-83.
Robbins, D. (2006). *Choice, control and individual budgets: emerging themes.* London: Social Care Institute for Excellence.
Social Care Institute for Excellence. (2010). At a glance 30: Personalisation briefing – Implications for NHS staff. Retrieved from http://www.scie.org.uk/publications/ataglance/ataglance30.asp.
The Health Foundation (2010). *Personal Budgets: Research Scan*. London: The Health Foundation.
The Health Foundation (2011). *Improvements in Practice: The Personal Touch. The Dutch experience of Personal Health Budgets.* London: The Health Foundation.
TLAP (2017). *Gathering the Evidence: Making Personal Budgets work for all.* Accessed from: https://www.thinklocalactpersonal.org.uk/Latest/Gathering-the-Evidence-Making-Personal-Budgets-Work-for-All-report/
Tyson, A., Brewis, R., Crosby, N., Hatton, C., Stansfield, J., Tomlinson, C., Waters, J., & Wood, A. (2010). *A report on In Control's Third Phase: Evaluation and Learning 2008-2009*. London: In Control Publications.
van Ginneken, E., Groenewegen, P. P. & McKee, M. (2012). Personal healthcare budgets: what can England learn from the Netherlands? *British Medical Journal*, 344.
Webber, M., Treacey, S., Carr, S., Clark, M., & Parker, G. (2014). The effectiveness of personal budgets for people with mental health problems: a systematic review. *Journal of Mental Health, 23*(3), 146-155.
Welch, E., Caiels, J., Bass, R., Jones, K., Forder, J., & Windle, K. (2013). *Implementing personal health budgets within substance misuse services: Final Report*. London: Department of Health.

Author accepted copy

Welch, E., Jones, K., Caiels, J., Windle, K., & Bass, R. (2017). Implementing personal health budgets in England: a user-led approach to substance misuse. *Health and Social Care in the Community, 25*(5), 1634-1643.

Whiteford, M., Cornes, M., & Williamson, I. (2016). Fulfilling Lives in Islington and Camden: Year 2 - Rapid Evaluation - Themes and Issues.

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Text box 1: Overview of personalised budget initiatives (The Health Foundation, 2010; NHS, 2015)

Direct payment – a cash payment given to an individual in lieu of directly providing services they have been assessed as needing to give them greater choice about their care. Individuals with DPs may employ people and commission services for themselves, taking on the responsibility for paying wages, meeting minimum wages and establishing contracts of employment.

Individual budget – a payment given to an individual for them to purchase the services or equipment they need to meet their assessed care needs. They differ to personal budgets as they cut across various funding streams including adult social care, disabled facilities grants, independent living funds, access to work and community equipment services, rather than focussing solely on health or social care.

Personal budget – funding allocated to an individual to spend as they wish on support and services to meet their social care needs. Individuals are responsible for choosing how their care needs are met and by whom. Recipients do not necessarily buy services or manage the funding themselves as the budgets can be held by a commissioner, managed on the individual's behalf by a third-party organisation, or provided as a direct payment to the individual.

Personal health budget - funding allocated to an individual to support the identified healthcare and wellbeing needs, which is planned and agreed between the individual, or their representative, and the local clinical commissioning group. It isn't new money, but a different way of spending health funding to meet the needs of an individual.

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Table 1: Subject headings and free text search terms used (Medline database)

Dimension	Search terms
Substance use headings	Exp substance-related disorders/ or Alcoholism/ or drinking behaviour/ or alcohol drinking/ or drinking/ or binge drinking/ or Alcohol-related disorders/ or alcohol intoxication/ or Amphetamine-related disorders/ or amphetamine/ or cocaine-related disorders/ or cocaine/ or crack cocaine/ or cannabis/ or heroin/ or heroin dependence/ or street drugs/ OR
Substance use free text words	((alcohol* or narcotic* or heroin or opiate* or opioid* or opium or cocaine or cannabis or marijuana or marihuana or hash* or phencyclidine or PCP or benzodiaz* or barbiturate* or amphetamine* or methamphetamine* or MDMA or ecstasy or hallucinogen* or ketamine or LSD or inhalant* or substance*) adj (abus* or misus* or us* or problem* or depend* or addict* or disorder*)) or illegal drug* or illicit drug* AND
Personalisation and personal budget headings	Exp Patient centred care/ or Budget/ or resource allocation/ OR
Personalisation and personal budget free text words	Person centred car* or Person-centred car* or Personali*ation or Personali*ed budget* or Personali*ed allocation* or Personali*ed or Personal health budget* or PHB or PHBs or Personal budget* or Individual budget* or Budget* or Direct payment* or Direct health budget* or Consumer-directed car* or Consumer directed car* or Self-directed support* or Self directed support* or Self-directed car* or Self directed car* or Cash for car* or User led choice* or User-led choice* or Conditional budget* or Notional budget*

* Denotes truncation of search term

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Table 2: Academic databases searched and the number of records identified

Database	Number of records
Medline (OVID)	1270
Medline ahead of publication (OVID)	27
PsycINFO (OVID)	766
EMBASE	2330
CINAHL	650
Web of Science	1650
Total	**6693**

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Figure 1: PRISMA flowchart detailing the review process

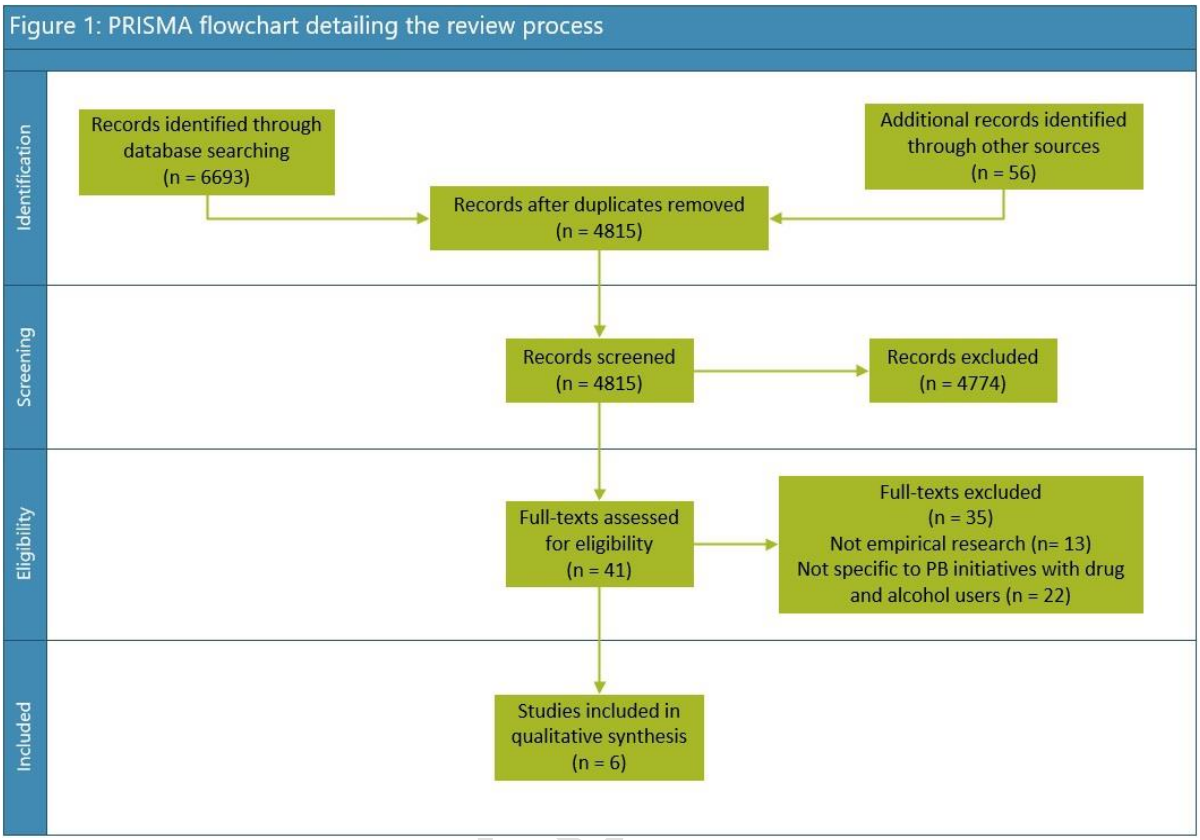

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Table 3: The Critical Appraisal Skills Programme scores

CASP Question	Yes	No	Can't tell
Is there a clear statement of research aims?	6	0	0
Is a qualitative methodology appropriate?	6	0	0
Was the research design appropriate to address the research aims?	6	0	0
Was the recruitment strategy appropriate to address the research aims?	6	0	0
Was the data collected in a way that addressed the research issue?	6	0	0
Has the relationship between the research and participant been adequately considered?	0	6	0
Have ethical issues been taken into account?	3	2	1
Was the data analysis sufficiently rigorous?	3	0	3
Is there a clear statement of findings?	6	0	0
Is the research valuable?	5	0	1

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Table 4: Summary of included studies								
#	**Reference**	**Type of budget**	**Amount of budget per person**	**Study aim**	**Study location**	**Study design and methods**	**Study population**	
							Service users	**Staff**
1	Callanan et al. (2012)	Self-directed support (SDS)	Site 1: £1,000 per year Site 2: used a Resource Allocation System to allocate funding based on assessed need. The allocations were: Band A £550-650/ week Band B £200-250/ week Band C £50-100/ week Band D £25-40/ week Band E £0/ week The average budget was £100/ week	To explore how self-directed support was implemented and experienced by service users and staff in 2 pilot sites	Nationwide, England	**Qualitative**: Semi-structured, face to face interviews; telephone interviews; focus groups	n= 16 (9 from site 1, 7 from site 2) over 2 different stages of the programme (face to face interviews)	n= 21 stakeholders (11 from site 1, 10 from site 2 over 3 different stages of the programme (face to face interviews and focus groups) n= 11 delivery staff over 2 different stages of the programme (7 from site 1, 4 from site 2) (face to face interviews, telephone interviews and focus groups)
2	Cornes, Whiteford & Manthorpe (2015)	Personal budget (PB)	£1,000 per year	To provide initial internal and external stakeholder feedback on the early development and progress of the Fulfilling Lives business plan	London, UK	**Qualitative**: Semi-structured, face to face interviews; telephone interviews; focus groups	n= 8 (6 face to face interviews, 2 telephone interviews)	n= 9 external stakeholders (telephone interviews) n= 17 staff (9 link workers; 4 Peer Development Board members; 4 peer mentors) (in 4 focus groups)

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3	Croft & Parish (2016)	Self-directed support (SDS)	**Medicaid/ Medicare/ veterans:** approx. £1,250 per year ($1,600) **Uninsured participants:** approx. £2,300 ($3,000)	To explore participants' experiences of self-directed support	Unidentified, US	**Qualitative**: Semi-structured, face to face interviews	n = 30 (face to face interviews)	None
4	Welch et al. (2013)	Personal health budget (PHB)	**Mean budge**t = £1,503 Between £200 - £500 = 25 people Between £501 - £1,000 = 17 people Between £1,001 - £5,000 = 41 people Between £5,001 - £10,000 = 2 people Between £10,001 - £17,000 = 4 people	To explore whether PHBs had an impact on outcomes and experiences compared to conventional service delivery among individuals with substance misuse	Unidentified, UK	**Qualitative:** Semi-structured, telephone interviews at two different time points **Quantitative :** Controlled trial with 12-month follow-up	n = 18 at baseline (10 receiving PHBs; 8 controls - not receiving PHBs) (telephone interviews) n = 8 at 9-month follow-up (6 receiving PHBs; 2 controls - not receiving PHBs) (telephone interviews) **Quantitative:** 55 with drug & alcohol users; 111 only with alcohol use	n = 10 (3 project leads; 2 commissioners; 2 healthcare professionals; 2 operational staff; 1 support worker) (telephone interviews)

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5	Welch et al. (2017)	Personal health budget (PHB)	N/A	To explore the experiences of organisational representatives responsible for implementing PHBs	Unidentified, UK	**Qualitative**: Semi-structured telephone interviews	None	n = 10 (3 project leads; 2 commissioners; 2 healthcare professionals; 2 operational staff; 1 support worker) (telephone interviews)
6	Whiteford, Cornes & Williamson (2016)	Personal budget (PB)	£1,000 per year	To explore how the Fulfilling Lives Islington and Camden (FLIC) programme deliver PBs to people with substance dependence	London, UK	**Qualitative**: Semi-structured, face to face interviews; telephone interviews; focus groups	n = 5 (face to face interviews)	n = 5 (3 frontline staff; 2 senior managers (face to face interviews) n = 5 local stakeholders) (telephone interviews) n = 6 link workers (in 2 focus groups)

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