10 *The service user as manager of care: the role of direct payments and personal budgets*

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Introduction

Direct payments and personal budgets have gained prominence in a range of countries as a means to strengthen the role of people in their own care and support (Gadsby, 2013). The origin of personal budgets can be traced to the independent living and disability rights movements in western countries in the 1970s that argued for greater self-determination and the right of people with disabilities to make decisions about the services that affect their lives. Subsequently, the concept of 'user-directed care' (which includes personal budgets and direct payments) was widened to include other target populations such as older people and people with long-term care needs, and, more recently, to health care (Gadsby, 2013; Kodner, 2003; Tilly & Wiener, 2001). Most commonly, personal budget schemes were introduced as part of a move towards personalization of care promoting choice, independence and autonomy by giving individuals control of a budget to purchase services to tailor their care to meet their specific needs (Gadsby, 2013).

This chapter traces the evolution of personal budgets and similar schemes in health and social care, describes the different types of scheme that have been implemented in different countries, explores the approaches that have been used and the goals different schemes are pursuing, and assesses the evidence of the impact of personal budgets and similar schemes on outcomes and their role towards more person-centred health systems. The chapter concludes with a set of recommendations to inform further research and policy. The chapter will not address 'medical savings accounts' which have emerged in a different context in response to concerns around inefficiencies in the private health insurance market, such as escalating costs, moral hazard, adverse selection and gaps in coverage (Hsu, 2010).

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Personal budgets: defining terms and concepts

The terminology of what can be broadly subsumed under the heading of personal budgets varies widely across countries and includes, in addition to 'personal budgets' (Germany, the Netherlands, England), and 'direct payments' (England), concepts such as 'cash and counseling' (United States of America), 'cash payments for care' (Germany), 'cash for care' (France), 'personal assistance budgets' (Belgium), 'cash payments' (Austria), 'home care service vouchers' (Finland), 'assistance allowances' (Sweden), 'individualized funding' (Canada) and 'consumer directed care' (Australia), among others (Forder et al., 2012; Kaambwa et al., 2015).

As the terminology varies, so do the nature, scope and target populations of the different schemes that have been implemented in different countries. This variation reflects, mainly, differences in contexts between countries in terms of structures, organization, and financing of health and social care systems, along with differences in societal values and cultures. At the same time, personal budgets and related schemes share some commonalities, in general seeking to promote choice, independence and autonomy, and the personalization of health and social care more broadly (Alakeson et al., 2016). For ease of flow, this chapter uses the term 'personal budgets' throughout as an overarching concept, which we define as 'an amount of money to be spent by individuals to purchase services to tailor care to meet specific needs'.

Independent from the type of model used, Gadsby et al. (2013) identified four 'primary' motivations for introducing personal budget schemes including: (1) giving individuals more choice; (2) expanding the options for care; (3) improving outcomes; and/or (4) reducing expenditures. Underlying these motivations is the assumption that more choice will lead to greater autonomy, which will in turn improve outcomes at lower costs. Other motivations may include efforts to reduce the fragmentation of services, to stimulate private sector provision, or to improve the family's capacity to take on caring responsibilities (European Platform for Rehabilitation, 2013).

As noted, by allowing individuals to decide on how to spend an allocated budget, they have – at least in theory – more choice, control and flexibility over the services they wish to use and that best meet their individual needs (Gadsby, 2013). In practice, however, the degree to which people have choice and control varies. In general, two models can be identified (Alakeson, 2010). At the one end there are 'open models'.

In such programmes, individuals are allocated cash payments that they can choose to spend how they wish, and there are few or no accounting mechanisms in place. The only condition is that the individual must obtain adequate care and this is monitored at regular points in time. Examples of such models can be found in Austria, Germany and Finland (Alakeson, 2010). At the other end are the 'planned or budgeted models'. These programmes provide for a more direct connection between an individual's needs and the goods or services purchased. There are a number of restrictions on how the money can be spent, in that individuals must account for purchases against an approved spending plan by regularly submitting a record of the purchases, or limitations may exist in the types of goods or services that can be purchased. Examples of this type of model can be found in Canada, England, the Netherlands and the USA. Personal budget schemes may also contain elements of both models, such as in Belgium or France (Alakeson, 2010).

There are different ways in which personal budgets can be managed. These are:

1. direct payment model (or direct payments): the individual as the budget holder receives a cash payment or vouchers to purchase services or support (Health Foundation, 2010);
2. third party payment model: the budget is held by a third party service (for example, a professional, care manager or broker) who will assist the individual to access funding; service provision is monitored according to an approved care plan (European Platform for Rehabilitation, 2013);
3. notional budget model: commissioners are responsible for purchasing services, but the individual is aware of the treatment or service options and the corresponding costs (Welch et al., 2016); and
4. combined model: this model combines one or more features of models 1–3.

Personal budgets in practice: an overview of country experiences

This section provides an overview of recent developments in personal budgets and related schemes in Australia, Belgium, England, the Netherlands, Scotland, Sweden and the USA. This selection of countries was informed by an earlier analysis of such schemes in England, Germany, the Netherlands and the USA by the Commonwealth Fund

(Alakeson, 2010), and broadened to also include countries for which information was available in English or Dutch. Germany was excluded as there was only little published information in English available. We excluded Canada from this analysis as disability policy and service provision are determined at the provincial level, with different solutions developed across provinces, making an overview of Canada difficult. We recognize that other countries have also introduced personal budgets or similar schemes – including Austria, Denmark, Finland, France, Italy and New Zealand – but we were unable to identify sufficiently robust information that would allow satisfactory presentation of these schemes.

The principal features of each scheme are summarized in Table 10.1. As highlighted earlier, countries differ in the nature and scope of personal budget models and in the drivers behind the introduction of such schemes. Overall, however, the main idea or driver is to place the individual, who receives a certain amount of funding, at the centre of the process of identifying needs and making choices over the services they expect to best meet their needs. Other drivers include, among others, cost savings (Australia), reducing care home admissions (Belgium), and strengthening the private sector and diversification in the care market in particular, so increasing service options (the Netherlands). Differences with regard to organizational boundaries, eligibility criteria, funding structure and target populations were also observed. For example, target populations differ in terms of age group ('older people' in Australia, 'youth' in the Netherlands), in terms of care needs and nature of 'disability' (e.g. 'long-term care needs' in Belgium, England and the USA; 'physical or mental disabilities' in Sweden, 'psychiatric problems' in the Netherlands). In all but one country (Australia), the budget can be managed in more than one way (e.g. direct payments and budgets held by third parties in England, the Netherlands, Scotland, Sweden and the USA). There is a tendency in the literature to use different terms as they relate to the person receiving the personal budget interchangeably, such as 'individuals', 'people', 'users', 'persons', 'participants', 'patients' (Gadsby et al., 2013; O'Shea & Bindman, 2016; Pike, O'Nolan & Farragher, 2016). Pragmatically, we use the term 'individual' throughout this chapter.

Australia

The origins of personal budgets in Australia can be traced to a 2011 report by the Productivity Commission, which highlighted that the disability support arrangements in place at that time provided fairly limited

Table 10.1 *Overview of the use of personal budgets in a number of countries*

Country	Scheme	Drivers	Target populations	Budget deployment	Financial reporting
Australia	self-directed care	choice and control; cost savings	people with disabilities; older people	provider holds the budget	depends on the type of support
Belgium	personal assistance budget; personal budget	choice; autonomy; reduce care home admissions	people with long-term care needs	notional budgets; direct payments	depends on the type of support
England	personal (health) budget; direct payment	choice; autonomy; personalization of health and social care	people with long-term needs	direct payments; budgets held by commissioners or third parties	detailed financial accounting
the Netherlands	personal budget	choice and control; address limitations in current system; stimulate private sector provision	people with long-term needs; disability; psychiatric problems; youth	direct payments; budgets held by third parties	financial accounting
Scotland	self-directed care; direct payments	choice and control; recovery; rehabilitation	people in need of social care	direct payments; budgets held by third parties	compulsory accounting, but varies according to locality
Sweden	assistance allowances	personalization; autonomy; choice	people with severe physical or mental disabilities	direct payments; budgets held by third parties	limited responsibilities for the patients
USA	cash & counselling; self-directed care	expand options for home- and community-based long-term care	older people; disabled people with long-term care needs	direct payments; budgets held by third parties	detailed financial accounting

choice to individuals with disabilities (Productivity Commission, 2011). This was followed, in 2013, by the National Disability Insurance Scheme Act, which aimed to give individuals 'true' choice and control over "care and support that is objectively assessed as being reasonable and necessary over the course of their lifetime", including the ability to manage their own funding (Pike, O'Nolan & Farragher, 2016). The driving force behind the legislation was a perceived need to halt the rising costs of the national disability system (Pike, O'Nolan & Farragher, 2016). More recent years saw the introduction, in 2015, of consumer-directed care, including publicly subsidized home care services that are designed to assist individuals aged 65 years and older to remain independent. The individualized budget is managed by an approved provider on behalf of the individual. A control and decision-making framework outlines how the individual should, in conjunction with their provider, manage their care plan and the services they receive (Kaambwa et al., 2015). The plan distinguishes between 'general' and 'reasonable and necessary' support. The former refers to coordination, strategic or referral service or activity over which the individual has a high degree of flexibility regarding provision and implementation. Reasonable and necessary support is more narrowly defined in that the funding and the way in which related services are to be provided are specified to help ensure that expected outcomes are attained. Funds can be used for services that are aimed at pursuing individuals' goals, maximizing their independence and their ability both to live independently and to be included in the community as fully participating citizens. Support services will not be provided or funded if they are likely to cause harm to the individual or pose a risk to others (Pike, O'Nolan & Farragher, 2016).

Belgium

The foundations for personal budgets in Belgium were set in 1997, with the introduction of a pilot programme for individuals with disabilities to enhance their autonomy in managing their own care. However, it was only in 2000 that the Flemish government developed a legal framework for the introduction of personal assistance budgets for disabled individuals (Breda et al., 2004; Flemish Government, 2015). From 2017 this scheme switched to a two-phase system consisting of a 'basic support budget' ('basis ondersteuningsbudget') and a 'personal budget' ('persoonsvolgende budget'). The major drivers behind this

system can be seen to be situated within a shift towards more demand-driven care and support for the disabled. There was also an expectation that personal budgets would reduce the demand for care home places (Flemish Government, 2013). The 'basic support budget' consists of a fixed amount of funds aimed at individuals with a disability with limited care needs. The budget can be used for home-based support or transport services, and this does not need to be formally reported. The 'personal budget' is personalized and directed at disabled individuals with intensive or recurring care needs. It involves the agreement of a care plan between the individual and the Flemish Agency for People with a Disability which sets out the types of service that are required. The budget is determined based on a needs assessment tool, using parameters that correspond with nationally fixed budget levels. Funds can be obtained in cash, through a voucher, or a combination of both (Flemish Agency for People with a Disability, 2017).

England

Direct payments were first introduced by the 1997 Community Care (Direct Payments) Act. It was targeted at working age disabled individuals with long-term care needs. Eligibility was subsequently expanded to include older individuals (2000), parents of disabled children (2001), and those with mental health problems (2009) (Alakeson, 2010; European Platform for Rehabilitation, 2013). In 2007 personal budgets were further promoted as part of the new approach to adult social care to reduce public spending in social care (Government of the United Kingdom, 2007). This was followed, in 2009, by the piloting of personal budgets within the National Health Service (NHS), and the 2014 Care Act created a legal framework for the development of care and support for all adults with needs for care and support. The personal budget pilot provided for a spectrum of flexibility for individuals in managing their budget. Thus, eligible individuals could choose whether to manage the budget themselves (direct payments) or use a third party to do so on their behalf (Department of Health, 2014; Department of Health, 2015; NHS England, 2015). As some individuals included in the pilot also used funds to purchase health-related services, the government introduced a further pilot scheme for personal health budgets, which operated from 2009 to 2012 (Alakeson et al., 2016; European Platform for Rehabilitation, 2013).

Similar to personal budgets and direct payments in social care, eligible individuals could choose to receive the funds as a direct payment, or have the funds managed by the NHS or by a third party (Gadsby, 2013; NHS England, 2015). Following completion of the pilot phase, personal health budgets were introduced from 2013 for individuals with diabetes, chronic obstructive pulmonary disease, Parkinson's disease, and serious mental illness receiving long-term complex care (Forder et al., 2012; Gadsby, 2013). From October 2014 personal health budgets were to be rolled out to include all individuals eligible for continuing health care (Department of Health, 2012). Central to the scheme is a care plan which is planned and agreed between the individual (or their representative) and the local clinical commissioning group (the purchasers of most care in the English NHS). Individuals can choose to manage their personal health budgets in different ways depending on the level of financial responsibility they wish to take (Alakeson et al., 2016). Individuals have considerable freedom in the services they can purchase, ranging from home-based support services to psychological and physical therapies, as well as nursing services, transport services and leisure activities (O'Shea & Bindman, 2016). The budgets are typically determined by using 'indicative budgets' based on best estimates and/or previous care packages. Local authorities are responsible for setting the level of funding to meet the individual's needs (Gadsby, 2013; Pike, O'Nolan & Farragher, 2016).

In April 2015 the Integrated Personal Commissioning Programme was launched as a partnership between NHS England and the Local Government Association. It is aimed at individuals with high health and social care needs. A key element of the programme consists of personalized commissioning and payment enabling a wider range of care and support options tailored to individual needs and preferences (Bennett, 2016).

The Netherlands

Active promotion and campaigning by the patients' rights and disability movements in the 1980s and 1990s paved the way for personal budgets in the Netherlands (Pike, O'Nolan & Farragher, 2016). In 1995 personal budgets were introduced for individuals with disability, chronic illness, mental health problems, or age-related impairments (European Platform for Rehabilitation, 2013) and regulated under the long-term

care legislation (Pike, O'Nolan & Farragher, 2016). Individuals were required to complete a needs assessment to justify their choice of services (European Platform for Rehabilitation, 2013) and also submit a care agreement. In 2007, under the 'Social Support Act', municipalities were given responsibility for personal budgets to fund domestic care (Pike, O'Nolan & Farragher, 2016). A relaxation of the accounting requirements in the early 2000s led to a substantial growth in overall costs and since 2014 only those who would otherwise have had to move into care or a nursing home were able to keep their personal budget or apply for one. The new mechanisms allowed individuals to keep tailored services, but financial limits were defined by the authorities (Alakeson, 2010; European Platform for Rehabilitation, 2013). In 2015 the system was further reformed with personal budgets allowed under the following acts:

1. the 'Long-term Care Act', for people with severe long-term care needs including vulnerable old people and people with severe disabilities. The budget can be used for intensive care or close supervision, with care determined based on a needs assessment;
2. the 'Social Support Act', which aimed at enabling people to live independently and to participate in society. The municipalities determine how social support is delivered;
3. the 'Youth Act', which includes personal budgets for mental health care, parenting support and social support for children less than 18 years old. The municipalities are responsible for the budget; and
4. the 'Healthcare Insurance Act', which included additional benefits for a number of services such as nursing care, care related to sensory disabilities (low vision, blindness, deafness), and inpatient mental health care.

The Dutch government, the municipalities and the health insurers are jointly responsible for long-term care, including personal budgets. The vast majority of personal budget payments are made under the 2015 Social Support Act. Personal budgets for elements of long-term care and for nursing care are also covered under the Long-term Care Act and the Healthcare Insurance Act respectively (Government of the Netherlands, 2015; Pike, O'Nolan & Farragher, 2016). The personal budget schemes have been designed explicitly to stimulate private sector provision of care services (Pike, O'Nolan & Farragher, 2016).

Scotland

The 'Community Care and Health Act 2002' introduced direct payments for social care that aimed at providing greater independence for eligible individuals (Ridley et al., 2011). Following this, the 10-year strategy 'Self-directed care support: a national strategy for Scotland' was introduced in 2010 focusing on the delivery of care and support for all categories of individuals in need of social assistance, including people with disabilities, and also for caregivers. It was assumed that involving carers in the assessment process of required care for the individual can help identify and deliver support that is personalized, preventative, responsive and sustainable. This would then lead to greater satisfaction with the process and can contribute to improved outcomes for the individual, as well as for the carer (e.g. stress relief, improved quality of life). This strategy promoted choice and control and linked these concepts to the goals of recovery and rehabilitation (Scottish Government, 2010). In 2014 the 'Social Care (Self-directed Support) Scotland Act 2013' came into force, which provided for direct payments (Scottish Government, 2014). Local authorities determine the amount of money that individuals may receive as a direct payment and for which services they can be used. 'Eligible needs' are established according to national eligibility criteria that determine the level of these needs. Services can include care from a personal assistant or family member, nursing care, housing support services, equipment and adaptations (Pike, O'Nolan & Farragher, 2016).

Sweden

In 1993, following campaigns by the Swedish Independent Living Movement and as part of a broader disability policy reform, two acts were established: the 'Act concerning Support and Service to Persons with Certain Functional Impairments' and the 'Assistance Benefit Act'. The Acts' main objective was to provide support for people with severe physical or mental disabilities so they could live like others in the community. Personal assistance budgets, through direct payments (based on assistance hours), were established in 1994, subject to the personal assistance needs of the individual and without means-testing. Thus, payments are made without consideration of personal or family income. When applying for assistance individuals have to submit an assessment by a physician that describes their functional disabilities

and the impact they have on their quality of life. Eligible patients can choose to receive direct payments, purchase services from their municipalities or private bodies, or privately employ personal assistants. The payment can be used for 'fundamental needs' and other activities, such as assistance with household tasks, work, childcare or leisure activities. There are few restrictions on how the money can be spent, but budget-holders are required to send a monthly report on the number of hours of work performed by the assistants (Gadsby, 2013; Independent Living Institute, 2010).

The United States of America

Many US states have financial and care assistance programmes, usually associated with Medicare, which provide the beneficiary with cash assistance and with the flexibility to self-direct the spending of the cash on care providers of their choosing. Formerly called 'Cash and Counseling', this model is now referred to as 'Consumer Direction', 'Participant Direction', 'Self-Directed Care' and a variety of other state-specific names.

The term 'Cash and Counseling' originated in the mid-1990s – with a pilot run in fifteen states – aiming to give Medicaid beneficiaries with disabilities the flexibility to self-direct the spending of the cash on care providers of their choice (American Elder Care Research Organization, 2017). The target population consisted of children, adults and older people with disabilities who were eligible for personal care or home-based and community-based services (Alakeson, 2010). The budget is managed by third-party financial management organizations to improve financial control and simplify the accounting process (Doty, Mahoney & Simon-Rusinowitz, 2007; O'Shea & Bindman, 2016). The budget is determined by an assessment of the number of care hours required and is then calculated using the number of care hours and cost of care for a geographic area. The budget can be increased or decreased as the individual's needs change. The budgets can be used for some health care services (e.g. nursing, rehabilitation) and for hiring and supervising of personal assistants for a specified number of hours per week aimed at reducing the demand for places in care homes (Kaambwa et al., 2015; O'Shea & Bindman, 2016). Since the success of the pilot, the model has been adopted in many states, as 'IndependentChoices' in Arkansas, 'In Home Supportive Services' in California and 'Choice Waiver' in Michigan.

Personal budgets: considerations

Personal budgets and similar schemes are about making the financial aspect of care more explicit at the individual level. By allowing the individual to determine how to spend the money, personal budgets can offer more choice and control to the budget-holder (Gadsby, 2013). However, there are a number of considerations that may impede the success of personal budgets, including: if increasing consumer choice leads to confusion; if people are unable to access the relevant information and support to make informed choices; and whether health professionals are comfortable in acknowledging patients' preferences, which may be different from their own (Gadsby et al., 2013).

Although personal budgets can increase an individual's sense of control and choice, and the money can be used in a more flexible way to respond to each individual's needs, allowing patients to determine which services they want to use poses the risk of them choosing services that increase rather than decrease their problems. For example, personal budgets can be spent in ways that do not conform to the current understanding of evidence-based medicine. There is yet a risk that the budget is spent on care that is ineffective or at worst even harmful and as a consequence is not meeting the needs of the patient. Moreover, increasing choice is accompanied by a number of responsibilities, constraints and consequences resulting in individuals losing a certain amount of security when third parties determine their needs, or even increased uncertainty (Spandler & Vick, 2006).

There are also concerns that complicated personal budget programmes may even reduce control and oversight for some service user groups (Ungerson, 2004). People without the ability or capacity to manage a personal budget themselves, or without the necessary support, risk being less able to benefit from, or being excluded from, access to such financial allowances (Galpin & Bates, 2009). So, a key element for the implementation of effective personal budget schemes is the availability of professional support (Welch et al., 2016). The need for support may, however, vary across different target populations. For example, older people and people with complex needs may need more extensive support to help them to manage their personal budgets effectively, particularly when direct payments are used (Health Foundation, 2010). In contrast, younger adults with physical disabilities have been found to be more capable in managing personal budgets themselves (Wise, 2016).

At present, there is only limited research examining the benefits of personal budgets for different demographic groups or people with different health conditions. There is only little comparative information available, suggesting that personal budget schemes are more effective for particular target groups (for example, Wise, 2016). Further, concerns remain for people who lack the capacity to manage their personal budget themselves. Family members or third parties may act as representatives, but they need to act in the best interest of the individual. Involvement of third parties is preferable if concerns exist about financial exploitation by family members (Alakeson et al., 2016; European Platform for Rehabilitation, 2013). However, in the Netherlands the involvement of third-party organizations, in the form of independent support brokerage agencies, was found to be problematic because they employed aggressive marketing tactics (Gadsby, 2013).

The availability of accurate information is crucial to make an informed choice; however, substantial differences in the availability of such information exist between countries. For example, in an evaluation of the use of personal budget schemes in 11 OECD countries, it was concluded that necessary information was not available in countries with more 'open models' because the provision of information was not incorporated into these programmes (Gadsby et al., 2013). Another consideration is the extent to which patients may want to make decisions about the services they want to use. For example, the findings of a review by Auerbach (2001) suggested that patients want information, but do not necessarily want to make decisions. This is congruent with the findings of a study that examined the experiences of receiving and using a budget by 58 English NHS patients with long-term conditions. An important factor that contributed to a sense of satisfaction with the budget was the feeling that 'somebody cared'. A number of respondents reported that they felt uncomfortable making choices about their health care and strongly argued for more professional support (Davidson et al., 2013). No evidence exists related to 'best practices' in terms of providing information, training or support to service users. Therefore, future research could examine the 'optimal support dose', which may vary across individuals, target populations and/or health conditions.

Other challenges persist which may prevent the successful implementation of personal budget schemes. The introduction of personal budgets often challenges the current way of working and it may take considerable time and effort to ensure successful implementation. Indeed, personal

budget programmes may require substantial change across a number of existing service systems. Furthermore, the uptake by individuals is difficult to predict and may be slower than anticipated (Gadsby, 2013). Although some countries have endeavoured to expand personal budgets to include health care services (so-called 'personal health budgets'), concerns have been expressed that such an extension may pose the risk that governments will use such budgets to cap spending on health care and transfer the risk of unexpected health care needs to the individual (Alakeson, 2010). Flexible capacity is needed for personal health budgets because health systems need to be able to reallocate resources in favour of those services selected by patients in directing their own care. If this extra capacity is not available, then patients' choices will be limited (Appleby, Harrison & Devlin, 2003).

Personal budgets: what do we know about their effectiveness?

This section reviews the evidence on personal budgets, focusing in turn on their impact on: (1) choice and control, (2) health outcomes, (3) quality of life and well-being, and (4) costs and cost-effectiveness.

Do personal budgets enhance choice and control?

Webber et al. (2014) examined the literature on the impact of personal budgets for individuals with mental health problems. In five of the 15 studies included in the review the impact of personal budgets on choice and control was reported, with four studies (Eost-Telling, 2010; Hatton & Waters, 2011; Spandler & Vick, 2004; Teague & Boaz, 2003) observing an increase in the levels of perceived control and choice. Conversely, a survey by Cheshire West and Chester Council in England in 2010 found that individuals receiving a personal budget felt less in control of their care and support compared to other social care groups (Cheshire West & Chester Council, 2010). Davidson et al. (2013), referred to earlier, examined the experiences of 58 patients with long-term conditions of the effect of personal health budgets using a qualitative study design. The majority of interviewees reported increased choice and control, while only a minority commented that the personal health budget had no impact on perceived choice and control. The latter generally reflected a lack of understanding or lack of information about the nature and purpose of the budget. The majority of the budget-holders did not

know whether their budget was adequate or not because they did not know the initial budget allocation or how much money was left. Nine months after receiving the money, about 50% of respondents felt that the level of the budget was adequate for their needs. This was mainly because a part of the budget was still available or because all services had already been purchased.

Welch et al. (2016) examined the perceptions of 10 organizational representatives in implementing personal health budgets for people with substance misuse problems in England. The interviewees reported that choice and control were likely to increase through the option of selecting providers who were not available within conventional health care delivery. It was also felt that providers had become more responsive to the needs of clients and that patients had increased responsibility for their own care. However, a number of challenges and concerns were identified. First, it was reported that increased choice and control had resulted in increased stress and anxiety, rather than empowering individuals. A second concern was related to the types of services that could be purchased. Study participants commented that more guidance was required. About 80% of the budgets were managed notionally and it was felt that direct payments would ensure more flexibility because such payments were considered as the only option allowing individuals absolute control over their budget. Moreover, direct payments were perceived as the only option that would allow individuals absolute control over their budget. The representatives responsible for implementing personal health budgets also expressed concerns about the inappropriate use of funds, particularly if the requested support did not conform with professional or evidence-based knowledge. Glendinning et al. (2008) evaluated the individual budget pilot programme from 13 local authority sites in England. The target population included adults and seniors with physical, cognitive and psychiatric disabilities who were eligible for long-term care and other disability support services. They found that patients continued to purchase traditional services such as home care; however, greater choice and control was experienced.

Larsen et al. (2015) evaluated the experiences with personal budgets of 47 psychiatric patients receiving care from integrated teams. Only four respondents reported a perceived loss of choice. Spandler & Vick (2006) examined the views of 58 mental health service users receiving direct payments. They identified improved levels of choice, control and independence. Breda et al. (2004) evaluated the impact of personal

assistance budgets in the Flanders region (Belgium) three years after implementation. The introduction of this type of personal budget scheme resulted in an increased degree of choice. However, a discrepancy was observed between the needs and the available services, particularly for services for which only limited alternatives in formal care were available. Personal assistance budgets were also associated with a considerable administrative burden.

Do personal budgets improve health outcomes?

A comprehensive analysis by Forder et al. (2012) examined the impact of the personal health budget pilot programme in England. Their findings suggest that the programme did not result in a significant impact on health status (assessed as blood glucose in diabetes patients and lung function in chronic obstructive pulmonary disease patients) or on mortality. Gadsby et al. (2013) evaluated the impact of personal budgets in 11 OECD countries and concluded that improvements in health are possible but more evidence is needed.

In examining the perceptions of patients with long-term conditions, Davidson et al. (2013) found that the majority of respondents reported improvements in health across a range of domains that was far wider than the condition for which the money was given, including better care arrangements and better relationships with health professionals. In an evaluation of the 'Cash and Counseling' programme in the USA, 6700 older adults and younger people with disability-related needs were randomized to a self-directed programme or to a traditional agency-based programme. In the 'Cash and Counseling' arm, similar or better health outcomes were achieved compared with the agency-based programme (Boston College, 2017). Jones et al. (2013) compared the introduction of personal budgets in the UK to conventional health care delivery. The aim of the introduction of the personal budgets was to secure a series of services and support such as home-based care, transport or therapies, but no significant associations between group changes in health outcomes and mortality were found.

Do personal budgets improve quality of life and well-being?

Evaluations of personal budget programmes in Australia, England and the USA suggest that such schemes may improve satisfaction, well-being

and some aspects of quality of life (Gadsby et al., 2013). A literature review examining the impact of personal budgets for individuals with mental health problems reported mixed findings. Some evidence related to the impact of personal budgets on quality of life, satisfaction and mental health was found, but this was not unequivocal (Webber et al., 2014).

Welch et al. (2016) identified a number of benefits associated with personal health budgets, including increased self-confidence and self-esteem and the potential to rebuild shattered lives. Larsen et al. (2015) described the most commonly reported positive outcomes as including mental and emotional well-being (reported by 34 of 47 participants), and confidence and skills (reported by 28 participants). Only four participants also reported negative outcomes such as stress and bureaucracy. Spandler & Vick (2006) found improved well-being in a sample of mental health service users receiving direct payments. Jones et al. (2013) and Forder et al. (2012) both evaluated the personal health budget pilot programme in England as noted earlier. Jones et al. (2013) found no significant differences between an intervention group receiving personal budgets (n=1171) and a control group receiving conventional health care delivery (n=1064) in health-related quality of life. In contrast, psychological well-being significantly improved in the intervention group compared to the control. Mixed results were also observed by Forder et al. (2012), such that for health-related quality of life no significant improvements were found, while the use of personal health budgets was associated with a significant improvement in care-related quality of life and psychological well-being.

Do personal budgets reduce costs and and provide value for money?

Gadsby et al. (2013) reported mixed findings on the impact of personal budgets on costs. On the one hand, personal budget schemes can result in short-term cost savings at an individual level. On the other hand, costs may rise if people purchase care for services previously bought out-of-pocket (substitution effect). The aforementioned review by Webber et al. (2014) of the impact of personal budgets for people with mental health problems identified two studies that reported on cost-effectiveness. These found personal budgets to be either cost-neutral (Glendinning et al., 2008) or cost-effective (Forder et al., 2012). In the latter study the

change from baseline to follow-up (at 12 months) in costs of inpatient care were found to be significantly higher in the personal health budget group compared to the control group (–£2150 vs. –£830, P=0.040). No significant between-group differences in changes in total costs were observed (intervention vs. controls: £800 vs. £1920, P=0.319). The personal health budget group showed greater benefit (0.057 vs. 0.018)[1] and lower total costs (£800 vs. £1920) compared to the control group. The authors noted that the findings of their study must be cautiously interpreted due to a number of methodological problems.

In summary, there is at present no conclusive answer to the question 'What is the impact of personal budgets and similar schemes on the outcomes of choice and control', 'health', 'quality of life and well-being', and 'cost and cost-effectiveness'. The available evidence suggests that personal budgets may have a positive impact on choice, control, quality of life and well-being, and to some extent on costs and cost-effectiveness, but this is far from unequivocal. Studies were characterized by heterogeneity in study designs. For example, only a small number of studies used a controlled design. It is clear that more research based on sound methodological principles is required. Such studies could examine both the effectiveness and cost-effectiveness of personal budget programmes in order to help inform policy development. Future research should also address the long-term consequences of such programmes and the development of a general framework for the evaluation of personal budget programmes and initiatives. This would enable better cross-country comparisons, while being mindful that it remains important to take country-specific contexts into account.

Conclusions

Personal budgets and similar schemes are an alternative way of purchasing elements of health and social care services, enabling individuals to shift from a passive recipient of care role to an active purchaser role. They can thus be considered as a mechanism towards more personalization in health and social care delivery. Originating from the independent living and disability rights movements, personal budget programmes have

1 Measured by the ASCOT (Adult Social Care Outcomes Toolkit). This measure is designed to capture information about an individual's social care-related quality of life.

been introduced in a number of countries. In general, they are aimed at promoting choice, control and independence for the service users by involving them in the planning and purchasing of health and/or social care. Considerable differences across countries persist in terms of eligible target populations, accounting mechanisms and budget deployments. This means that in some countries cash payments are provided to individuals directly while in other countries organizations retain responsibility for making payments in conjunction with the patients. The international evidence about personal budgets and similar schemes is rather limited. Some evidence was found that personal budgets can improve choice, control, well-being and quality of life. Evidence related to their impact on health outcomes, costs and value for money is scarce. For whom and how personal budget schemes could best be implemented and the related consequences of these choices remains inconclusive.

Recommendations

We provide some recommendations for policy and further research below. These are presented in an integrated way such that both sets of recommendations are combined. The reason for this approach is that the information derived from scientific research can serve as input for policy decisions.

It is important to clearly define the types of care and support services that can be purchased using personal budgets. Choices need to be made as to whether or not to limit the available options to only those for which there is an evidence base. As a starting point, one could consider excluding options for which there is no evidence or that are considered to be harmful. It is, however, important that there are appropriate options to meet the needs of individuals. Thoughtful consideration must go into the design of these programmes in order to minimize the risk of unintended consequences and counter the barriers hampering successful implementation. The information derived from scientific research can serve as a guiding tool to help determine which services can be purchased with personal budgets. Thus, further research should examine both the effectiveness and cost-effectiveness of personal budget programmes. Evidence about the effectiveness of strategies – i.e. which strategies work best for whom and under what circumstances – is currently insufficient to inform policy-making. Since governments face the challenge of priority setting in the allocation of scarce health

care resources, health economic evaluations of such payment schemes can provide payers and governments with improved insights on how to spend the available resources in the most efficient way.

'Informed choice' requires the availability of accessible and accurate information. This should include clear information about the amount of funds being allocated, the types of services that can be purchased with the personal budget, and related accounting requirements. Special attention should be given to target populations with limited ability or lack of capacity to enable them to participate fully in personal budget programmes. Financial support through personal budgets is only one approach towards more personalization in health and social care delivery. Personal budget schemes must be embedded in wider policies aimed at people with health and social care needs.

The origin of personal budgets lies in the independent living and disability rights movements of the 1970s that argued for greater self-determination and the right of disabled people to make decisions about the services that affect their lives. More recently, personal (health) budgets have also been discussed in the movement towards more integrated health and social care delivery for people with chronic conditions. In this context, personal (health) budgets are considered 'financial incentives'. Other incentives that may be more appropriate for integrated care include pay-for-performance, pay-for-coordination and all-inclusive payments (global budget and bundled payment). Therefore, the role of personal budgets in the movement towards greater integration of health and social care should be viewed within the larger picture of integrating (elements from) other financial incentives.

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