

Kent Academic Repository

Gadsby, Erica W., Segar, Julia, Allen, Pauline, Checkland, Kath, Coleman, Anna, Mcdermott, Imelda and Peckham, Stephen (2013) *Personal Budgets, Choice and Health – a review of international evidence from 11 OECD countries: A Review of International Evidence from 11 OECD Countries.* International Journal of Public and Private Health care Management and Economics, 3 (3). pp. 15-28. ISSN 2155-6423.

Downloaded from https://kar.kent.ac.uk/41307/ The University of Kent's Academic Repository KAR

The version of record is available from https://doi.org/10.4018/ijpphme.2013070102

This document version UNSPECIFIED

DOI for this version

Licence for this version UNSPECIFIED

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact <u>ResearchSupport@kent.ac.uk</u>. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our <u>Take Down policy</u> (available from <u>https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies</u>).

Personal Budgets, Choice and Health: A Review of International Evidence from 11 OECD Countries

Erica Wirrmann Gadsby, Centre for Health Services Studies, University of Kent, Canterbury, UK Julia Segar, Centre for Primary Care, University of Manchester, Manchester, UK Pauline Allen, London School of Hygiene and Tropical Medicine, London, UK Kath Checkland, Centre for Primary Care, University of Manchester, Manchester, UK Anna Coleman, Centre for Primary Care, University of Manchester, Manchester, UK Imelda McDermott, Centre for Primary Care, University of Manchester, Manchester, UK Stephen Peckham, Centre for Health Services Studies, University of Kent, Canterbury, UK

ABSTRACT

Personal or individual budgets for purchasing health and social care are intended to offer more choice, control and flexibility to service users when compared with agency-directed care. They are becoming an increasingly common feature in high-income countries for purchasing personal care that often lies on the border line between health and social care. In England, they have recently been introduced explicitly for the purchasing of health care. There are some key motivations behind their introduction: they are expected to give individuals more choice about care they receive; to expand options for care; to improve outcomes; and to reduce expenditure. This paper draws from a review of the international evidence on personal budgets which identified: descriptive detail on personal budget schemes in 11 OECD countries to examine their key features and implementation processes; empirical evidence on the experiences of, and outcomes for, people using these schemes, and; empirical evidence regarding the impact of the schemes on the healthcare system, particularly with regards to resources. The paper examines the motivating factors behind personal budget schemes in light of this evidence. It concludes that there is little in the evidence to suggest that international governments' expectations for personal budget programmes are well-founded. The assumptions that they improve choice, and that more choice will in turn lead to greater autonomy and then improved outcomes at lower cost, are actually far more complex and generally unsupported by evidence.

Keywords: Cash-For-Care, Health Policy, Patient Choice, Personal Budgets, Personalisation

DOI: 10.4018/ijpphme.2013070102

Copyright © 2013, IGI Global. Copying or distributing in print or electronic forms without written permission of IGI Global is prohibited.

INTRODUCTION

Most health and social care services are provided to service users as relatively passive recipients. Professionals decide which services are most appropriate for meeting the service user's needs. Local providers might hold a contract for the delivery of that service, and the service user will get little or no say in how, where and when that service is provided. Personal or individual budgets are an alternative way of purchasing elements of health and social care services. They bring money closer to the individual service user (either as a direct payment to be spent by the individual, or as a 'notional' budget to be managed by others), and by-pass the commissioning organisations that have historically spent the funds on agency-directed care. They are one of a number of mechanisms that can be used to help 'personalise' health and social care services and empower service users by making them more active consumers of care. By specifying the budget for an individual's care, and allowing that individual to decide how it should be spent, the personal budget (PB) theoretically offers more choice, control and flexibility to the budget holder. This leads to what is sometimes called 'self-directed' or 'consumer-directed' care.

PBs are rapidly becoming international phenomena, with many high-income countries experimenting with some form of individualised funding particularly for long-term care (Dickinson & Glasby, 2010) which often lies in the 'grey zone' between health and social care. This extension of the choice agenda is consonant with policies aimed at increasing competition within healthcare systems based on a belief that competition will drive down spiralling healthcare costs. Such policies are highly dependent on the ideologies of governments in power (Toth, 2010). Reflecting on waves of healthcare reforms in recent decades in six OECD countries, Toth (2010) notes that choice and competition initiatives were instituted by conservative governments in the early 1990s. In some countries (less so in England, where New Labour post-2006 supported the choice agenda), these were swept away by the subsequent leftof-centre governments' counter-reforms before their effectiveness could be ascertained. The return to power of conservative administrations in many of these countries in the 2000s has seen a return to "fashion" of the patient choice agenda. PBs fit squarely within this agenda implying that patients are consumers of healthcare, and as consumers are best placed to make choices about that care (Fotaki, 2007). The notion that healthcare is consumed in the marketplace in the same way as other goods and services has been widely critiqued (Greener, 2009; Lupton, 1997). Choice in healthcare requires patients to be informed, undertake 'work' involved in choice-making, take responsibility for their care, and shift relationships with clinicians. PB programmes vary enormously, but all converge on the principle of improving choice and control for service users by involving them in the planning and purchasing of care.

This paper reviews published work on PBs from 11 OECD countries. It focuses on programmes that can be used to purchase 'health' services (although distinctions between health and social care are far from clear cut, and definitions vary from country to country). It furthers the work of the Health Foundation who, in 2010, published a research scan (Health Foundation, 2010) which provided a brief synopsis of evidence on the impact of PBs on patient-centred care, health outcomes and value-for-money. The evidence available was largely subjective evidence regarding satisfaction and feelings of empowerment. Since that research scan, several government-led programmes have been piloted and evaluated, and the evidence base has been strengthened.

To build on the research scan, the objectives of this review were to identify: descriptive detail on PB schemes with a health remit in a range of OECD countries to examine their key features and implementation processes; empirical evidence on the experiences of, and outcomes for, people using these schemes, and; empirical evidence regarding the impact of the schemes on the healthcare system, particularly with regards to resources. It questions whether there is evidence that PBs deliver either definitive outcomes or cost savings. It also examines whether PBs offer choice or an illusion of choice to budget holders. Four common motivating factors behind the introduction of PB programmes in different countries are identified and examined in the light of international literature.

METHODS

This paper draws from a rapid review of the international evidence on PBs and health which was commissioned by the English Department of Health to address an urgent demand for synthesized evidence (Gadsby, 2013). A search was made of bibliographic databases, reference lists of identified articles and reviews, and the websites of relevant organisations for information available as of August 2012. In order to achieve a comprehensive search for relevant literature experts in the field were consulted for further literature and sources of evidence. The search and filtering processes prioritised the finding of literature related to using PBs to either purchase health services, or explicitly improve health outcomes. This limited the databases and search terms we chose to employ. The databases included Web of Knowledge, MEDLINE, the

Cochrane Library, Google Scholar, the WHO library, and Health Management Information Consortium. All databases were searched from 2008¹ until present using search terms such as 'personal health budgets', 'personal budgets', 'individual budgets', 'individualised budgets', 'individualised funding', 'cash-for-care', 'direct payment', 'consumer-directed care' and 'cash and counselling'. This rapid review was conducted within a short time-frame and therefore preference was given to the more readily available research published and written in English.

References were split into those only giving descriptive details of programmes, and those reporting on evaluations of programmes. Given the paucity of evaluative literature, evaluations of social-care related PBs were considered relevant, particularly in terms of enriching contextual and comparative detail. 280 references were considered relevant to the topic area. These included nine programme evaluation reports (see Table 1) and 28 reports of empirical research published in peer-reviewed journals. They also included 14 articles which offered a cross-national perspective. In total, these references provided sufficient information to report on programmes in 11 countries. A descriptive categorisation strategy was employed

Country	Programme	Evaluation
United States	Cash and counselling pilot	Randomised controlled trial (RCT) (Brown et al., 2007)
	Florida self-directed care	Matched-comparison design (Florida Department of Children and Families Mental Health Program Office, 2007)
	Empowerment initiatives brokerage evaluation	Base-line and follow-up surveys with participants and programme staff (very small sample) (Sullivan, 2006)
England	Individual budgets	RCT-based design (Glendinning et al., 2008)
	In Control evaluation of personal budgets	Aggregated findings from locally implemented evaluation questionnaires with budget holders (Tyson et al., 2011)
	Personal health budgets pilot	Non-randomised comparative design using mixed methods (Forder et al., 2012)
Canada	Individualised quality of life project	Non-comparative evaluation (Roeher Institute, 2000)
Australia	New South Wales direct funding pilot	Comparative evaluation (very small sample) (Fisher & Campbell-McLean, 2008)
	Government consumer- directed care initiative	Process evaluation, non-experimental design, some comparative data. (Gordon et al., 2012)

Table 1. Evaluation designs in different programmes

to collate, compare and contrast information on programmes in the 11 countries with respect to: their development, their primary motivations, their key features (related to rules for the use of the budget, eligibility criteria, accounting requirements, and types of support services provided), implementation issues, and reported outcomes.

Whilst the search identified sufficient descriptive information to summarise key features of programmes and comment on notable implementation issues in eleven countries², evidence on programme costs and outcomes was only available for England, the Netherlands, Germany, Canada, the US and Australia.

WHAT IS EXPECTED FROM PBS?

The introduction of PBs responds to the call for greater independence for physically and mentally disabled people and from a belief that 'tailoring' services to the needs and preferences of individuals empowers citizens. It is believed that this approach might improve outcomes and experiences for individuals (HM Government Policy Review, 2007).

As the Health Foundation (2010) note, most programmes aspire to reduce overall costs to health and social care, although different countries have varying motivations for introducing PBs. In England, Personal Health Budgets (PHBs) fit within a wider government agenda to promote choice, autonomy and personalisation of health and social care services. Most countries aim to increase the independence and freedom of choice of individuals by expanding the options available for home and communitybased long-term care. In Belgium, France, and Germany, there is an expectation that this will lead to reduced pressure for care homes, and therefore reduced costs. The Netherlands, Austria, and Finland are explicitly trying to promote private sector provision, or stimulate the care service markets to drive down costs and address limitations in the current system.

Four key motivating factors can be identified behind the programmes in the eleven countries examined here:

- To give individuals more choice about care/ services they receive;
- 2. To expand options for care/services, particularly to enable people in need of long-term care to stay at home;
- 3. To improve outcomes (particularly satisfaction, quality of life and health);
- 4. To reduce expenditure within the health and social care systems.

Behind these expectations lies an assumption that more choice will lead to greater autonomy, which will in turn improve outcomes at a lower cost.

A COMPARISON OF INTERNATIONAL PB PROGRAMMES

PB programmes differ internationally, with varying degrees of patient choice and control occurring in a variety of contexts. At one extreme, there are programmes in which cash payments are allocated with few strings attached and with no accounting mechanisms. Alakeson (2010) refers to this as an 'open' model. At the other extreme are programmes that maintain a more direct connection between a participant's needs and goods and services purchased. Restrictions are placed on how money can be spent, and the expenditure is audited carefully. This model - which Alakeson (2010) refers to as the 'planned' or 'budgeted' model - is more common. Between, and even within, these extremes there are important differences in programme features that interact with each other to either enhance or limit an individual's degree of choice.

Programmes in Austria and Finland, for example, are relatively 'open'. Whilst autonomy for individuals can be high, the actual degree of choice is limited in practice by the adequacy of budgets and availability of services. Where programmes are very simple and incorporate little or no support to budget holders, eligibility may also be restricted to those who are able to manage their own budgets without professional support.

Programmes in England, the Netherlands, the US, Canada and Germany, on the other hand, are more 'planned', and involve considerable input from commissioners/providers with the aim of increasing individual autonomy. These programmes link the budget setting process to a personalised care plan, require spending plans to be authorised, and require expenditures to be accounted for. They all incorporate various support services for budget holders, and often include a number of options for budget deployment to help ensure the suitability of the programme for a wider range of users. Whilst the theoretical level of individual autonomy is high in these countries, the actual degree of choice is limited. This might be through the adequacy of the budget, or through the complex processes involved in implementation. Processes that affect choice include: the extent to which the development of a personalised care plan is holistic, and focused on the individual's goals; the authorisation processes for spending plans; and the detail and complexity of financial reporting procedures. These are highly dependent on attitudes of staff within local organisations, and the performance measures against which they are judged.

Whilst the English PHB programme shares programmatic features with others, it is different in several important ways. First, the overall budget comes from the NHS, so has a more explicit 'health' focus: in England, budget holders must demonstrate that the services they choose will help to meet specified *health* outcomes. Second, in the English programme, there are comparatively very few restricted items – complementary therapies, leisure activities and purchases like a computer are all permissible. Finally, in England, the PHB is intended to be sufficient to meet *all* the health needs identified in the care plan, without recourse to personal contributions. In all other systems, individuals are required or expected to contribute towards the budget.

Several programmes fall between the 'open' and 'planned' models. In France and Belgium, individual assessments are carried out, but are defined by professionals who check eligibility, and determine budget allocation based on nationally set tariffs. In France, budgets are allocated by direct payment. In Belgium, individuals can have a notional budget or a direct payment, but choice is not always theirs. In Sweden, the budget setting process is related to an evaluation of needs, but it is not clear whether personalised care planning plays a role. Individuals can find support from peer support groups, and can commission other organisations to take on employment responsibilities, but direct payments are the default deployment option. In the Australian programme, individuals go through a process of personalised care planning, but the budgets tend not to be closely linked to this, relating instead to operational guidelines. Individuals have relatively more choice only when the care planning process is more personalised and goal-driven, and where individuals are encouraged by providers to be innovative (Gordon et al., 2012).

This discussion leads us to examine further the expectation that PBs will give individuals more choice about the care/services they receive.

MEETING EXPECTATIONS: WHAT DOES THE EVIDENCE SAY?

Choice

The discussion above already highlights that the degree of real choice afforded to budget holders is dependent on preconditions. To exercise informed choice, individuals require accessible, accurate information. Information needs to be personalised to suit individual needs for decision support, and the design of the programme will have a strong bearing on how well they serve vulnerable populations. In the US, the 'counselling' element is integral to the PB programme (named 'Cash-and-Counselling') and has been credited with helping to ensure quality and control fraud (Doty, Mahoney, & Simon-Rusinowitz, 2007). In countries with a more 'open' model, the provision of information and decision support is not incorporated in the programmes. In most countries, accurate information to inform decisions may not be available.

The ability to exercise choice also depends on the availability of at least two positive alternatives. In some countries, this is limited by a lack of providers or a shortage of workers (e.g., in Finland, where there are few or no non-state providers in some rural areas). In France, the use of budgets is strictly controlled, limiting budget holders' choices. In other countries, like the US where budgets are capped, the size of the budget may be insufficient to offer real alternatives. Indeed, in all countries, the possibility of alternatives will be heavily dependent on the size of the budget. In the English PHB pilot programme, budget amounts varied hugely. Since most were too small to open up alterative care options, they tended to be used to purchase 'add-ons' to existing packages of care/support (Forder et al., 2012).

The extent to which PBs increase real choice has not been evaluated. Even assuming budget holders are given relatively free choice, information on how individuals spend their budgets is only rarely available and never in sufficient detail to allow comparisons with standard packages of care. In the US, there is some evidence that the increased flexibility in longterm care allows budget holders to purchase a greater diversity of goods and services than is available through traditional service delivery, and there is sometimes a shift away from some (clinical) categories of services in favour of others (often non-clinical) (Alakeson, 2007).

In the Australian pilot programme, PB holders chose similar types of support as those available under standard packaged care, and generally used their package for 'core services'. They exercised choice and control over how the services were delivered, including choice of support worker, and tasks undertaken by support workers. Some used part of their funds for innovative support (e.g., shower stool, lightweight vacuum cleaner). Provider attitudes to requests for supports that were different from the 'usual menu' of services varied (Gordon et al., 2012).

In the English pilot of individual social care budgets, the evaluation showed that many with PBs had purchased mainstream services (Glendinning et al., 2008). This was sometimes because they felt the amount of the budget was inadequate to cover any support over and above their personal care. Others felt they had fought hard for the services they were already receiving, and did not want to let these go. Some were anxious about spending their budgets on new services or different patterns of support. However, as in the Australian pilot, the budgets allowed people to exercise greater choice and control, even in the use of mainstream services (Glendinning et al., 2008).

In the English PHB pilot, the overall patterns of expenditure by budget holders showed that the majority of the money was spent on social care-related services, although spending patterns varied depending on the health condition of the budget holder. Budget holders were found to have changed the mix of services they secured, although these changes were relatively modest (Forder et al., 2012).

Options

The second expectation is that PBs will expand available options for care/services, particularly to enable people to stay at home. There is evidence, particularly in the US, that the availability of PBs has helped reduce nursing home use, giving people a wider range of options enabling them to stay at home (Dale & Brown, 2006). PBs are a good way to personalise services. Some English PHB holders liked being able to obtain voluntary, community or private sector

Copyright © 2013, IGI Global. Copying or distributing in print or electronic forms without written permission of IGI Global is prohibited.

services as an adjunct to NHS mental health services. Others arranged care services more suitable for them and their lifestyles (Davidson et al., 2012).

However, evidence also shows that PBs are not a panacea. Although some countries have introduced PBs explicitly to stimulate the market, this outcome has not necessarily followed. In the Netherlands, for example, expected developments in the market were not seen, and in some cases, options were reduced as the PB programme resulted in some providers merging (Kremer, 2006; White, 2011).

Creating more options will require flexible capacity. Responsiveness is essential if a health system is to be able to reallocate its resources in favour of the services or providers that people choose over others. But if extra capacity is not available to meet the new demand, some existing options may have to disappear, meaning those who gain from choice would do so at the expense of someone else's healthcare needs (Appleby, Harrison, & Devlin, 2003). Enthusiasm for PBs may also highlight deficits of agency-led care. For example, core mental health services are notoriously underfunded in many countries. PBs may be appreciated by individual service-users, but this popularity could also reflect shortcomings of funding and access to core services.

Outcomes

The third expectation is that PBs improve outcomes. The evidence demonstrating impacts of PBs on health and wellbeing is weak. Most of the evidence about this comes from the US and England, and suggests that some improvements are possible, but studies are far from conclusive and open to challenge (Health Foundation, 2010).

Evidence shows that PBs have little impact on health outcomes (using validated measures). The English PHB evaluation was the most rigorous to date, and used a wide range of validated measures, a mix of methods, and the 'difference in difference' approach to statistical analysis, which recognises that both intervention and control groups could differ at baseline and that other influences may apply during the course of the intervention (Forder et al., 2012). The evaluation found that the programme had no significant impact on health status³ or on mortality rates. Additionally, people in the PHB group did not report significant improvements in health-related quality of life (using EQ-5D) compared to those in the control group (Forder et al., 2012).

Similarly, evaluations of consumer-directed, compared with agency-directed, home-care in the US and Germany suggest largely unchanged health outcomes, despite the increased use of non-authorised care services (Arntz & Thomsen, 2011; Benjamin, Matthias, & Franke, 2000; Benjamin & Fennell, 2007; Brown et al., 2007; Robert Johnson Wood Foundation, 2006; Wiener, Anderson, & Khatutsky, 2007). This largely allays concerns about possible *harms* to health, although the available evidence is predominantly concerned with using PBs to purchase long-term *personal* care (e.g., dressing, bathing, toileting) rather than *health* care, where potentially more harm can occur.

Positive outcomes in terms of patient satisfaction, wellbeing, and quality of life are consistent conclusions of PB evaluations, although measurement of these is often subjective. Evaluations of PB programmes in the US, England and Australia have shown that service users who self-direct their home care arrangements gain control and express a higher level of satisfaction than those who receive agency-directed care (Benjamin et al., 2000; Carlson, Foster, Dale, & Brown, 2007; Fisher & Campbell-McLean, 2008; Foster, Brown, Phillips, Schore, & Carlson, 2003; Gordon et al., 2012; Tyson et al., 2011; Wiener, Tilly, & Cuellar, 2003). The English PHB evaluation (Forder et al., 2012) confirmed that these outcomes can also be achieved when extending self-direction into healthcare.

The evaluation found that there were significant positive effects of using PHBs on social care-related quality of life (measured using ASCOT), and psychological wellbeing (measured using GHQ12). However, qualitative data indicated that benefits were not universally felt, with some interviewees expressing frustration over curtailed choices, lack of services, lack of control over budgets and low levels of budgets (Davidson et al., 2012).

Evidence shows that PBs improve satisfaction and some aspects of quality of life for the majority of users, but the mechanisms by which this happens are not clear. There is no evidence to suggest which factors are most important in the implementation of PBs in order to optimise these outcomes. However, evaluation of English PHBs (Forder et al., 2012) found that their impact depends greatly on how the programme is implemented. Indeed, in sites where there was relatively little flexibility built into the PHB process, the evaluation found that PHBs had a *negative* impact on health-related quality of life, psychological wellbeing and subjective wellbeing.

Costs

The final motivating factor concerns costsaving. PB schemes across the world have often been supported by the belief that they could be an effective means of curbing or even driving down the costs of health and social care by delegating the control of budgets to the end user, and reducing the use of expensive residential or acute care.

The Health Foundation (2010) concluded that it is difficult to evaluate the cost or valuefor-money of PBs given the paucity of outcomes, information and accurate costings available. Though some studies have found reductions in health service use and resource costs, analysts suggest that many studies do not accurately cost comparison groups or fully account for implementation costs.

The English PHB evaluation (Forder et al., 2012) offers the most rigorous cost-effectiveness examination. The calculations were complex, resting upon important assumptions concerning monetary value placed on care-related quality of life, assessment of cost implications in terms of recurrent health and social care service use, and level of statistical significance. Also, the analysis ignored extra transaction costs that might accrue in using PHBs - an important limitation, as any scheme which incorporates mechanisms to support individuals making choices will carry with it significant transaction costs. The analysis showed some evidence that PHBs might be cost-effective if delivered in certain ways, and for certain people. PHBs implemented with a greater degree of flexibility were considered cost-effective, as were those with high-value budgets. However, few other conclusions could be drawn with confidence.

Like many other studies, the PHB evaluation (Forder et al., 2012) showed that PBs can lead to short-term cost savings at an individual level. However, it is not known how these come about. It might be that individuals are able to secure more cost-effective care. Or. those cost savings might reflect an individual: having less care to meet their needs; meeting fewer of their needs; or meeting their needs less adequately with cheaper care. The evaluation found evidence that some budget users' acute medical attendances decreased. There is no evidence to say whether these attendances have been avoided or merely delayed. It is important to remember that if an initiative is found to be cost-effective, it will not necessarily be costsaving. There is no good evidence about the capacity for PBs to reduce overall costs in the longer term.

In some countries (e.g., the Netherlands, Germany, the US), experience suggests that PBs could lead to rising costs related to the 'woodwork effect', where people whose needs were not being met by existing services find solutions in PBs. Costs may rise where people use the budget for things previously bought out of pocket (the 'substitution effect'). In many countries, such costs are controlled by reducing the value of the budget and increasing the proportion paid by the individual, or by restricting who can have a budget. In the English PHB programme, the principle of non co-payment and concomitant lack of restrictions on budget use might limit the ability to control costs in this system.

DISCUSSION

The international evidence-base on PBs is weak, and few firm conclusions can be drawn concerning their potential impact on health, costs or savings within the health and social care system. Evidence points to increased satisfaction and wellbeing for the majority of budget holders, although not necessarily better health. It also points to potential cost savings at the individual level, although the impact of these on quality, outcomes and longer-term costs are unknown.

PBs are supposed to offer service users more choice and control over their care. Whilst there is no evidence on the actual degree of choice realised by budget holders, we do know that it varies considerably within and between programmes, and is influenced by many factors. The rationale underlying these programmes is that choice is positive – it promotes independence and is arguably important for mental well-being (Arksey & Glendinning, 2007). It is assumed that a more tailored package, versus a 'one size fits all' approach to health care, produces a happier patient.

Whilst there is some evidence to support this assumption, these outcomes are far from guaranteed. Sometimes, efforts to enhance patient choice conflict with notions of 'good care' (Mol, 2008). Psychologists have also shown that whilst choice can lead to decisions that produce better outcomes, exercising choice can simultaneously cause anxiety and regret. From this perspective, choice is not good for psychological and emotional well-being (Schwartz, 2005).

There is no inevitable link between choice and quality. In fact, there are real concerns that greater choice may lead to reduced quality. Investigation into the impact of cash-for-care reforms in France, Germany, Italy, the Netherlands, Sweden and England suggest that the introduction of PBs has created room for low-quality employment to grow, making it difficult to control quality of both employment and care (Pavolini & Ranci, 2008). Research indicates that the Western European personal assistant labour market is characterised by migrant, mostly female workers with a high turnover. In Austria and Italy, where budget holders are allowed to spend their allowance as they choose, unregulated, 'grey' markets falling outside of employment law have emerged. Attempts at regulation to protect both employee and employer have varied in success (Carr & Robbins, 2009). Many programmes have no official system of supervising the quality of care (White, 2011).

Choice is not always valued in the same way; not all desire to take more control over choosing and purchasing services. Considerable evidence shows that many patients want information, but do not necessarily want to make decisions (Auerbach, 2001). One indication of the popularity of choice might be the take-up of PBs. In the Netherlands the scheme has been popular, but remains small, with most patients opting for the regular system. In England, the uptake of PBs for social care was slow until the government introduced ambitious and controversial targets (Samuel, 2013). Service users may not be clamouring to make more choices, even where they are dissatisfied with existing services. A possible explanation is that choicemaking requires energy and work (Mol, 2008).

The introduction of greater choice in practice raises many difficult questions: Does choice lead to confusion rather than clarity? What information and support enables people to make informed choices? How can it be ensured that choice is meaningful? How do health professionals feel about acknowledging patients' preferences, which may not be their own? What happens if people choose badly? Who should make decisions when people lack capacity to make their own? (Warner, Mariathasan, Lawton-Smith, & Samele, 2006). Answers to these questions are not always clear, but may prove to be instrumental in achieving any benefits.

There is another assumption around choice that focuses on its relationship with competition: if money follows the patient, patient choice will encourage providers to improve efficiency and quality. Again, evidence to endorse this assumption is weak. A review of the evidence on choice in healthcare concludes that there is neither strong theoretical nor empirical support for competition, although there are cases where competition has improved outcomes (Propper, Wilson, & Burgess, 2006).

There are also concerns about equity and its trade-off with choice. Choice emphasises the value of individuals' views. But in a publiclyfunded health service, collective or social values must inevitably take precedence. Individuals may choose services or treatments that best meet their preferences, but these might not be the most cost-effective, or reflect the preferences of society as a whole. Since resources for healthcare are finite, the individual's choice may have corresponding opportunity costs in terms of health gain foregone by other patients (Appleby et al., 2003). This is particularly important in England, where PHBs are currently funded by top-slicing existing health budgets, rather than from additional resources. Expansion of the scheme may therefore have knock-on effects on other health services. A further concern for equity is that the opportunities to exercise choice may be inequitably distributed, and the outcomes of those choices may lead to even greater inequalities. This can be mitigated partly by ensuring personalised support is available to budget holders, but this will increase costs.

The expectations of PBs rest on an assumption that more choice will lead to greater autonomy, which will in turn improve outcomes at a lower cost. However, greater autonomy might not be the only or most logical outcome of greater choice. In fact, increased choice might raise expectations, perhaps leading to reduced satisfaction or feelings of regret (2005). Greater choice can sometimes lead to indecision or 'choice paralysis', where people find it very difficult to choose at all (Schwartz, 2005). It is also evident that a range of intrinsic factors will influence people's choice making. In the qualitative data from the English PHB evaluation, many patients emphasised the wish to use their budget 'in the right way', and did not want to 'take advantage' of the scheme (Davidson et al., 2012).

Finally, it does not necessarily follow that greater autonomy will improve outcomes at a lower cost. It could in fact mean greater pressure to spend healthcare resources on goods/ services for which there is little/no evidence of efficacy or cost-effectiveness. There is no evidence to say what impact this will have on either outcomes or costs. In the current context of financial constraints and spiralling costs related to aging populations and the burden of 'lifestyle' diseases, PBs might be considered a risky strategy. There might be greater promise in health and social care organisations working together to use funds differently. The Better Care Fund in England is a promising example, where a single pooled budget has been created to support health and social care services to work more closely together in local areas (NHS England, 2014).

CONCLUSION

As the momentum for PBs builds, and they become an increasingly common part of the commissioning landscape in a number of countries, there are good reasons for policy makers to proceed cautiously. There is little in the evidence to suggest that international governments' expectations for PB programmes are well-founded. The assumptions that they improve choice, and that more choice will in turn lead to greater autonomy and then improved outcomes at lower cost, are actually far more complex and generally unsupported by evidence. Much more research is needed, in particular to examine the longer term consequences of PB programmes (particularly for health, cost and equity), and to help assess whether PB holding is the best way to achieve greater freedom, responsiveness and control for the patient.

DECLARATIONS

This article is based on research funded by the English Department of Health. The views expressed are those of the researchers and not necessarily those of the Department of Health.

REFERENCES

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

Alakeson, V. (2010). International developments in self-directed care. *Issue Brief (Commonwealth Fund)*, 78, 1–11. PMID:20232527

Appleby, J., Harrison, A., & Devlin, N. (2003). What is the real cost of more patient choice? London, UK: King's Fund.

Arksey, H., & Glendinning, C. (2007). Choice in the context of informal care-giving. *Health & Social Care in the Community*, 15, 165–175. PMID:17286678

Arntz, M., & Thomsen, S. L. (2011). Crowding Out Informal Care? Evidence from a field experiment in Germany. *Oxford Bulletin of Economics and Statistics*, 73(3), 398–427. doi:10.1111/j.1468-0084.2010.00616.x

Auerbach, S. M. (2001). Do patients want control over their own health care? A review of measures, findings and research issues. *Journal of Health Psychology*, *6*(2), 191–203. doi:10.1177/135910530100600208 PMID:22049321

Benjamin, A. E., & Fennell, M. L. (2007). Putting consumers first in long-term care: Findings from the cash and counseling demonstration and evaluation. *Health Services Research*, *42*(1 Pt. 2), 353–362. doi:10.1111/j.1475-6773.2006.00694.x PMID:17244287

Benjamin, A. E., Matthias, R. E., & Franke, T. M. (2000). Comparing consumer-directed and agency models for providing supportive services at home. *Health Services Research*, *35*(1), 351–366. PMID:10778820

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, NJ: Mathematica Policy Research, Inc. Carlson, B. L., Foster, L., Dale, S. B., & Brown, R. (2007). Effects of cash and counseling on personal care and well-being. *Health Services Research*, *42*(1), 467–487. doi:10.1111/j.1475-6773.2006.00673.x PMID:17244293

Carr, S., & Robbins, D. (2009). *The implementation of individual budget schemes in adult social care. Research briefing*. London, UK: Social Care Institute for Excellence.

Dale, S. B., & Brown, R. (2006). Reducing nursing home use through consumer-directed personal care services. *Medical Care*, 44(8), 760–767. doi:10.1097/01.mlr.0000218849.32512.3f PMID:16862038

Davidson, J., Baxter, K., Glendinning, C., Jones, K., Forder, J., Caiels, J., et al. (2012). *Personal health budgets: Experiences and outcomes for budget holders at nine months. Fifth interim report.* Department of Health / Personal Health Budget Evaluation team.

Dickinson, H., & Glasby, J. (2010). *The personalisation agenda: Implications for the third sector*. Third Sector Research Centre. Retrieved April 4, 2014, from http://www.birmingham.ac.uk/generic/tsrc/documents/tsrc/working-papers/working-paper-30.pdf

Doty, P., Mahoney, K. J., & Simon-Rusinowitz, L. (2007). Designing the cash and counseling demonstration and evaluation. *Health Services Research*, *42*(1), 378–396. doi:10.1111/j.1475-6773.2006.00678.x PMID:17244289

England, N. H. S. (2014). *Better Care Fund Planning*. Retrieved April 4, 2014 from http://www. england.nhs.uk/ourwork/part-rel/transformationfund/bcf-plan/

Fisher, K., & Campbell-McLean, C. (2008). Attendant care direct funding pilot project evaluation—final report. University of New South Wales & Disability Studies and Research Institute: Report for Department of Ageing, Disability and Home Care NSW, SPRC Report Series 11/08. Sydney.

Florida Department of Children and Families Mental Health Program Office. (2007). *Report on the effectiveness of the self-directed care community mental health treatment program*. Florida Department of Children and Families Mental Health Program Office.

Forder, J., Jones, K. C., Glendinning, C., Caiels, J., Welch, E., Baxter, K., et al. (2012). *Evaluation of the personal health budget pilot programme*. Department of Health / Personal Health Budget Evaluation team. Foster, L., Brown, R., Phillips, B., Schore, J., & Carlson, B. L. (2003). Improving the quality of medicaid personal assistance through consumer direction. *Health Affairs*, *W3*, 162–175. http://content.healthaffairs.org/content/early/2003/03/26/hlthaff.w3.162. long Retrieved April 4, 2014 PMID:14527250

Fotaki, M. (2007). Patient choice in healthcare in England and Sweden: From quasi-market and back to market? A comparative analysis of failure in unlearning. *Public Administration*, *85*(4), 1059–1075. doi:10.1111/j.1467-9299.2007.00682.x

Gadsby, E. W. (2013). *Personal budgets and health: A review of the evidence*. London, UK: Policy Research Unit in Commissioning and the Healthcare System. Retrieved April 4, 2014, from http://www.prucomm. ac.uk/our-publications

Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., & Knapp, M. et al. (2008). *Evaluation* of the individual budgets pilot programme: Final report. University of York. UK: Individual Budgets Evaluation Network, Social Policy Research Unit.

Gordon, C., Leigh, J., Kay, D., Humphries, S., Tee, K., Winch, J., et al. (2012). *Evaluation of the consumer-directed care initiative - Final report* KPMG. Retrieved April 4, 2014, from http://www. health.gov.au/internet/main/publishing.nsf/Content/ F072F0C75198E936CA257BF0001A35BF/\$File/ CDC-Eval-Final-Rep.pdf

Government, H. M. Policy Review. (2007). Building on progress: Public services. London, UK: Prime Minister's Strategy Unit.

Greener, I. (2009). Towards a history of choice in UK health policy. *Sociology of Health & Illness*, *31*(3), 309–324. doi:10.1111/j.1467-9566.2008.01135.x PMID:19055589

Health Foundation. (2010). *Personal health budgets: Research scan*. Health Foundation. Retrieved April 4, 2014, from http://www.health.org.uk/public/ cms/75/76/313/2594/personal%20health%20budgets.pdf?realName=wiYPsk.pdf

Kremer, M. (2006). Consumers in charge of care: The Dutch personal budget and its impact on the market, professionals and the family. *European Societies*, 8(3), 385–401. doi:10.1080/14616690600822006

Lupton, D. (1997). Consumerism, reflexivity and the medical encounter. *Social Science & Medicine*, 45(3),373–381. doi:10.1016/S0277-9536(96)00353-X PMID:9232732 Mol, A. (2008). The logic of care: Health and the problem of patient choice. New York, NY: Routledge.

Pavolini, E., & Ranci, C. (2008). Restructuring the welfare state: Reforms in long-term care in Western European countries. *Journal of European Social Policy*, *18*(3), 246–259. doi:10.1177/0958928708091058

Propper, C., Wilson, D., & Burgess, S. (2006). Extending choice in English health care: The implications of the economic evidence. *Journal of Social Policy*, *35*(04), 537–557. doi:10.1017/S0047279406000079

Robert Johnson Wood Foundation. (2006). *Choosing independence: A summary of the cash and counseling model of self-directed personal assistance services*. Princeton, NJ: Robert Johnson Wood Foundation.

Roeher Institute. (2000). *Individualized quality of life* project: Final evaluation report. Roeher Institute.

Samuel, M. (2013). Expert guide to direct payments, personal budgets and individual budgets. Retrieved February 26, 2013, from http://www.communitycare. co.uk/articles/30/01/2013/102669/direct-paymentspersonal-budgets-and-individual-budgets.htm

Schwartz, B. (2005). *The paradox of choice: Why more is less*. HarperCollins.

Sullivan, A. (2006). *Empowerment initiatives brokerage: Service quality and outcome evaluation*. Oregon Technical Assistance Corporation.

Toth, F. (2010). Healthcare policies over the last 20 years: Reforms and counter-reforms. *Health Policy (Amsterdam)*, *95*(1), 82–89. doi:10.1016/j. healthpol.2009.11.006 PMID:19963298

Tyson, A., Brewis, R., Crosby, N., Hatton, C., Stansfield, J., & Tomlinson, C. et al. (2011). *A report on In control's third phase: Evaluation and learning* 2008-2009. London, UK: In Control Publications.

Warner, L., Mariathasan, J., Lawton-Smith, S., & Samele, C. (2006). *Choice literature review: A review of the literature and consultation on choice and decision-making for users and carers of mental health and social care services.* King's Fund and Sainsbury Centre for Mental Health.

White, C. (2011). Improvement in practice: The personal touch. The Dutch experience of personal health budgets. The Health Foundation.

Wiener, J. M., Anderson, W., & Khatutsky, G. (2007). Are consumer-directed home care beneficiaries satisfied? Evidence from Washington State. *The Gerontologist*, *47*(6), 763–774. doi:10.1093/geront/47.6.763 PMID:18192630

2

3

Wiener, J. M., Tilly, J., & Cuellar, A. E. (2003). Consumer-directed home care in the Netherlands, England and Germany. Washington, DC: AARP Public Policy Institute.

ENDNOTES

¹ 2008 was used as a start date for the searches to reflect the fact that this work would be building on the Health Foundation review (2010), and that the researcher's time was limited. However, where particularly useful and important evidence and other background literature from pre-2008 was identified, this was not excluded.

- The countries included in the review are: Austria, Belgium, England, France, Germany, the Netherlands, Canada, the United States, Australia, Sweden and Finland.
- Two clinical measures were used a blood glucose test for the diabetes cohort, and a lung function test for the Chronic Obstructive Pulmonary Disease cohort.

Erica Gadsby has wide-ranging experience in public health-related research and practice. Following graduate and post graduate studies in Social Policy, Sociology, Research Methods and Public Health, Erica completed a PhD in public health policy. She has worked in Uganda on a large-scale public health programme, has been involved in a range of international health policy/systems research projects, and has undertaken a number of technical assistance projects for the World Health Organisation and others in Africa and Asia. She is now at the Centre for Health Services Studies, and works as part of the Policy Research Unit in Commissioning and the Healthcare System. She has a keen interest in evidence-informed policy making.

Julia Segar studied and taught social anthropology and conducted fieldwork in both rural and urban areas in South Africa. Her PhD at the University of Manchester was a study of complementary and alternative therapists and their patients and explored their understandings of efficacy. She now works as a qualitative researcher and has worked on projects concerned with telehealthcare, policy changes in the healthcare system and the changing structures within the English Public Health system. She is a member of the Health Policy, Politics and Organisation group (HiPPO) in the Centre for Primary Care at the University of Manchester.

Pauline Allen is Reader in Health Services Organisation at the London School of Hygiene and Tropical Medicine. Following a degree in Politics, Philosophy and Economics at Oxford University, she qualified as a solicitor and practised company commercial law for some years. Later she started an academic career by working in an NHS district public health department and writing a PhD on the legal and economic aspects of the NHS internal market. Her research interests include socio-legal theory, institutional economics, organisational theory and the structure of the NHS. Current and recent research projects include studies of NHS foundation trusts, contracting in the NHS and the increasing diversity of types of providers to NHS patients. She has published widely on these issues in peer reviewed journals and books. Kath Checkland qualified as a doctor in 1985, and then trained as a GP. She subsequently did a PhD which focused upon the impact of National Service Frameworks in General Practice, and took an organisational approach, focusing upon the nature of general practices as small organisations. Her research has subsequently focused upon the impact of national health policy on primary care organisations. She still works 1 day a week as a GP in a rural practice in Derbyshire. She is a member of the Health Policy, Politics and Organisation group (HiPPO) in the Centre for Primary Care at the University of Manchester.

Anna Coleman has worked in a variety of policy and research roles within local government. She moved into academia in 2000 and subsequently completed a PhD focusing on the development of local authority health scrutiny. Her work has included a wide range of research, external consultancies, literature reviews, lectures and workshop facilitation. Her research interests include health policy, commissioning, partnership working, patient and public involvement, accountability and governance. She is a member of the Health Policy, Politics and Organisation group (HiPPO) in the Centre for Primary Care at the University of Manchester.

Imelda McDermott studied for her PhD in theoretical and applied linguistics at the University of Edinburgh. Her thesis used discourse analysis to critically examine medical news reports in the media. She has brought her knowledge and skills of discourse analysis to bear on health policy. Her current area of work and research is on clinical commissioning and recent reforms in the NHS. She is a member of the Health Policy, Politics and Organisation group (HiPPO) in the Centre for Primary Care at the University of Manchester.

Stephen Peckham is Professor of Health Policy and has a joint appointment as Director of the Centre for Health Services Studies and as Professor of Health Policy at the London School of Hygiene and Tropical Medicine. He is Director of the Department of Health funded Policy Research Unit in Commissioning and the Healthcare System a joint research unit based at LSHTM, the University of Manchester and CHSS. Stephen has over twenty years of academic research experience and previously worked in local government and the voluntary sectors. From 2002 to 2006 he was a non-executive director of a Primary Care Trust and has been a member of a number of research commissioning boards for NIHR and national charities. His main research interests are in health policy analysis, organisational and service delivery, primary care and public health.