Evidence scan:

Personal health budgets

September 2010

Identify Innovate Demonstrate Encourage

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Health Foundation evidence scans provide information to help those involved in improving the quality of healthcare understand what research is available on particular topics.

Evidence scans provide a rapid collation of empirical research about a topic relevant to the Health Foundation's work. Although all of the evidence is sourced and compiled systematically, they are not systematic reviews. They do not seek to summarise theoretical literature or to explore in any depth the concepts covered by the scan or those arising from it.

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Key messages

Personal health budgets encourage people to purchase and manage their own care, within a set budget. The aim is to increase choice and reduce overall costs.

This research scan collates more than 60 articles about personal health and social care budgets in the UK and internationally. The purpose is to provide a brief synopsis of evidence to help gauge the level of research in this field so far.

The scan addresses the following questions:

- What does the international evidence tell us about the impacts of personal health budgets on health outcomes, patient-centred care and value for money?
- Are personal health budgets more effective for some groups of people?
- Where do the majority of studies come from?
- What is the UK evidence about individual budgets for social care?

This research shows that the amount of high quality research available to guide policy and practice is limited.

The scan found that personal budgets are implemented differently in various countries. Sometimes people are given cash payments to spend as they wish. Alternatively, organisations keep responsibility for making payments but service users state what they want purchased on their behalf.

There is some evidence that personal budgets help people feel more confident and empowered because they are taking control of decisions over their care.

Evidence about impacts on health outcomes and service use is mixed. There is limited information about value for money, largely because there are few rigorous effectiveness studies and the costs of traditional care and personal budgets tend to be underestimated.

The majority of international studies come from the US, Germany and the Netherlands. But an important body of literature has examined social care budgets and direct payments in the UK. This literature points to differences in implementation across the four countries of the UK and suggests, to be successful, personal budgets need to offer adequate infrastructure, staff training and signposting, and support to service users. Older people may be more likely to find managing their own budget a burden.

Most of the information available is descriptive rather than empirical research and there are particular gaps around impacts on health outcomes and cost effectiveness. The literature suggests this approach may be worth exploring further.

Criterion	Rating
Relevance to priorities across the UK	Green
Potential to have real patient and cost outcomes	Yellow
Quantity of evidence available	Red
Quality of evidence available	Yellow
Availability of other evidence summaries and guidelines	Yellow

1 Scope

This research scan summarises readily available research about personal budgets in health and social care, with an emphasis on lessons learned internationally.

1.1 Purpose

The Health Foundation wants to explore what international evidence says about the potential for personal budgets to improve health and give people control over managing their health and their treatment.

A wide range of terms have been used to describe this approach to care, but throughout the scan the term 'personal budget' is used generically to refer to all similar approaches.

The key questions addressed are:

- What does the international evidence say about the efficacy of personal budgets for better health or improved health outcomes for people with long-term conditions?
- What does the international evidence tell us about the effects of personal budgets for improving patient-centred care? Do patients have greater control over their health and their treatments?
- Does the evidence tell us whether personal budgets offer value for money, such as evidence that costs per patient are reduced by enabling people to purchase what they judge they need?
- Where do the majority of studies come from – which countries are developing personal budget programmes?
- Has anybody explored which patient groups (or perhaps families or carers) benefit the most from personal budgets?
- What does the published research tell us about individual budgets for social care in the UK?

This section outlines the methods used to collate information. The following sections address each of the questions above briefly.

1.2 Method

To collate evidence, two reviewers searched bibliographic databases, reference lists of identified articles and reviews and the websites of relevant agencies for information available as at August 2010. The search, analysis and narrative synthesis were completed over a three week period.

The databases included MEDLINE, Ovid, Embase, the Cochrane Library and Controlled Trials Register, PsychLit, Google Scholar, the WHO library and the Health Management Information Consortium. All databases were searched from inception until present using search terms such as personal health budgets, individual budgets, individualised budgets, cash for care and patient held budgets.

Only studies or abstracts available in English were eligible for inclusion due to the lack of time available for translation. We identified some descriptive articles in German that were not able to be included as a result, but these did not appear to include empirical findings.

We scanned more than 10,000 pieces of potentially relevant research, selecting the highest quality and most relevant to summarise here. No formal quality weighting was undertaken within the scan, apart from the selection process outlined above. More than 60 studies and descriptive overviews were synthesised, covering both health and social care.

Data were extracted from all publications using a structured template and studies were grouped according to key questions and outcomes to provide a narrative summary of trends.

Meta-analysis was not appropriate given the context of the scan and the heterogeneity of the material. No other detailed empirical reviews specifically on this topic were identified, although a number of descriptions of personal health budgets are available and there are syntheses of research about individual budgets in social care.

When interpreting the findings it is important to bear in mind several caveats. The research scan is not exhaustive. It presents examples of studies and interventions but does not purport to represent every international study about personal budgets.

It is difficult to draw conclusions about the usefulness of personal budgets given the paucity of empirical research. Even where empirical studies were available, the level of detail was sometimes insufficient to provide a meaningful summary. A lack of evidence does not necessarily indicate a lack of effect, just that there may be few high-quality studies available from which to draw conclusions.

The empirical evidence did not usually define personal budgets in any depth. The approaches in various countries may differ somewhat, and it is difficult to draw comparisons without finding out more about how the systems are run. There is also a paucity of comparative evidence so it is difficult to say whether personal budgets may be more or less effective than alternative initiatives.

These caveats are all important when considering the synthesis of material overleaf.

2 Description

This section provides a brief overview of how personal budgets operate to set the scene. It also outlines which countries have published research about these initiatives.

2.1 Definitions

Personal budgets aim to empower people regarding the treatment and services they receive by encouraging them to take control over how money is spent on their care. This does not necessarily mean giving people the money itself. Personal budgets can work in many ways, including:

- a ring-fenced budget held by a commissioner such as the PCT or GP
- a budget managed on the individual's behalf by a third party
- a cash payment to the person or their carer (this is also known as a 'direct payment').

Other common terms to describe these schemes are personal health budgets, individual budgets, direct payments, consumer-directed care, self-directed support, cash for care, cash and counselling and personalised allocations.

In the literature, terms such as direct payments and personal health budgets are often used interchangeably. From an academic perspective there are some distinctions that are briefly outlined here.

Direct payments are cash payments given to service users in lieu of directly providing services they have been assessed as needing. The aim is usually to give service users greater choice about their care. Funds must be spent on services that people need. Direct payments mean that service users employ people and commission services for themselves, taking on the responsibility for paying wages, meeting minimum wages and establishing contracts of employment.

In England, direct payments for social care were introduced in 1997 for adults of working age and were extended to older people in 2000. Since 2001, direct payments have been available to carers, parents of disabled children and 16 and 17 year old service users. People with short-term needs such as people recovering from an illness or those with a disability are also eligible.

From 2003, councils were required to offer direct payments to everyone using community care services. These direct payments are means tested, so in many cases people contribute to the cost of their care. This means testing is similar to that undertaken for services commissioned and provided by local authorities. The direct payments approach has also been tested in healthcare in countries such as the US and Canada.

In contrast, personal budgets are an allocation of funding given to service users to spend as they wish, but the service user does not necessarily take responsibility for buying services. In this model, service users can take their personal budget as a direct payment or they can leave councils or third party organisations with the responsibility for organising and paying for services, whilst still choosing how their care needs are met and by whom.[1]

The introduction of personal budgets to the UK is part of the wider personalisation or person-centred care agenda in adult social care and healthcare. Although in use in social care for some time, the policy shift towards testing personal budgets for healthcare in England is relatively recent. The White Paper, 'Our health, our care, our say' and other contemporaneous documents suggested that individual budgets for healthcare were unlikely to be introduced. However during the NHS Next Stage Review, managers and clinicians in each SHA region considered how to improve pathways of care for service users and carers and as part of this process, a number of regions proposed testing personal health budgets. The Next Stage Review final report, 'High Quality Care for All' therefore announced a pilot programme to test personal health budgets in the NHS beginning in 2009.

More than half of the primary care trusts in England applied to participate in the personal health budgets pilot programme and about 63 sites are taking part in the pilot which runs from 2009 to 2012. Twenty of these sites have been selected to take part in an evaluation exploring the potential of personal health budgets for different groups of people.[2]

An interim report about the personal health budgets evaluation released in July 2010 focused on process issues when setting up the scheme.[3] The evaluators found that budget setting, care planning, management and accountability, cultural shifts, integrating health and social care, and workplace impacts have posed implementation challenges.

Factors that appear to facilitate implementation include:

- ensuring that finance departments are on board
- designing a clear process to support direct payments
- engaging NHS leaders, middle managers, clinicians, health professionals, providers and patients to manage the cultural shift required
- workforce training
- setting up a peer support system to help budget holders
- having a clear understanding of the cost of previous care packages and managing double running costs when expenditure is not disaggregated from existing contracts.

Individual budgets have a special meaning in the UK context because they cover a multitude of funding streams including adult social care, disabled facilities grants, independent living funds, access to work and community equipment services. Individualised budgets were first considered in the early 2000s as a way of personalising services and were initially targeted at people with learning difficulties. The distinguishing feature of individual budgets is that they cut across various funding streams rather than focusing solely on healthcare or social care as is often the case with personal budgets.

2.2 Examples

The scan identified more than 60 studies about personal budgets in health and social care. The majority of studies and descriptive material was from the US, the Netherlands, the UK and Germany. A small number of studies from Australia, Belgium, Canada and elsewhere were also included.

It is important to note that just because a country is not listed here does not mean that personal health budgets are not being tested, merely that no published empirical research was readily available about this during the scan period.

Nor does the number of studies described indicate which countries are more advanced in their testing. Rather, this merely indicates who is publishing descriptions or findings at present.

The scan found that personal budgets operate or are being tested in Austria, Australia, Belgium, Denmark, Germany, Italy, Finland, France, the Netherlands, Sweden, the UK and the USA, amongst others.[4] Each of these initiatives must be understood in the particular cultural and policy context of the country of origin.[5-8]

Most programmes aim to reduce overall costs to health and social care but different countries also have varying motivations for introducing personal budgets. Some initiatives focus on promoting independent living, whereas others aim to improve the family's capacity to take on caring responsibilities. In Belgium the aim was to reduce the use of expensive residential care.[9] In Australia, a programme was set up to reduce the fragmentation of services in remote, rural areas. And in the USA, some consumer-directed care have focused on reducing shortages of long-term care staff.[10,11]

Eligibility and target audiences also differ between countries. Some programmes are means tested whereas others are needs led.[12-14] In Canada, personal budgets focus most heavily on children and young people with learning disabilities, in Sweden adults with physical disabilities are targeted, and in the UK older people and those with disabilities or long-term conditions have been the main focus. [15,16]

The German, Dutch, French and Swedish systems are heavily regulated and include a case management, signposting or supportive counselling approach to help people get the most out of their personal budgets.[17]

For example, in the Netherlands elderly and disabled people in need of care can apply to a special municipal agency for care services.

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The agency decides which and how much of each service the person is entitled to, including domestic care, personal care, nursing or temporary residential care. The person can then decide whether to have the services delivered directly, receive a cash payment known as a personal budget or a combination of the two. Amounts up to €2,500 per year need not be accounted for and amounts over €2,500 per year must be used to pay people or agencies to provide care. Relatives can be reimbursed as long as there is a contract. In addition, people can receive a personal budget from a different municipal agency to help with housework, aids, mobility and wellbeing.[18]

In the USA the 'cash and counselling' system for people uses a similar personal budget approach but is available only for people with low income eligible for Medicaid.[19-21]

Germany has tested the feasibility and impact of using personal budgets for people in need of nursing care. About 1,000 people spread across seven regions took part in a pilot. Over a three year period people received a budget equivalent to what would be paid according to the German compulsory long-term care insurance. The budget was to be used exclusively for care-related services and could not be paid to family members or neighbours.

Initial analysis suggests that in order to be effective, personal health budgets should correspond to the individual level of care needed (which may change over time); be more flexible to allow input from neighbours and family members; and have quality assurance mechanisms in place from the outset.[22]

These differences between countries are important because they show that programmes have different aims and scopes so research findings cannot necessarily be generalised to other contexts.

Some comparative studies are available examining the similarities and differences of personal budgets in social care between England and other parts of Europe, but few similar reviews exist about healthcare.[23-25]

It has also been suggested that in most parts of Europe there are no formal legal procedures or policies in place to support personal budgets in health and social care. For instance in 2005-06, Mental Health Europe carried out a survey across Europe to examine whether personal budgets may be useful for people with mental health problems. The survey found that in the majority of countries, there is no legal framework for providing personal health budgets.[26]

3 Health outcomes

This section explores what the international evidence tells us about the efficacy of personal budgets for better health or improved health outcomes for people with long-term conditions.

3.1 Value of personal budgets

Perhaps surprisingly, there is a lack of readily available published literature about health outcomes and most is not explicitly about people with long-term conditions.

Studies from the USA found that people holding a personal budget and employing their own personal assistants were more likely to experience positive health outcomes, such as fewer falls and bedsores. These people were also more likely to use health services, perhaps due to identifying previously unmet needs or focusing more on prevention.[27-29]

It is uncertain whether managing their own budget or having personalised support from an assistant was the key success factor here.

In Florida, personal budgets with individualised support have been tested for people with mental health issues. An evaluation with a randomly selected comparison group examined hospital readmission rates, levels of satisfaction, service use, and community integration and interaction.

> *The evaluation revealed positive outcomes for self-directed care participants in terms of community integration and residential stability, both strong indicators of recovery and community functioning. Compared to non-participants, self-directed care participants also used significantly less crisis stabilisation unit and other crisis support services. Self-directed care participants had significantly higher numbers of assessments, medical services including psychiatry, outpatient psychotherapy services, and supported employment.*[30]

There was no difference in hospital readmission rates compared to the matched control group, but only a small number of people in the two groups were rehospitalised during the study period.

UK pilots in social care have also found some improvements in outcomes, as described in the next section.

3.2 Summary

Quality of evidence	Low
Quantity of evidence	Low

Do personal budgets improve health outcomes? There is not enough evidence to say whether personal budgets improve health outcomes. Most of the international evidence about this comes from the US and suggests that some improvements are possible, but the literature is far from conclusive and studies are small and open to challenge.

4 Patient-centred care

This section describes what the international evidence tells us about the effects of personal budgets on patient-centred care, with a focus on whether this approach helps people have greater control over their health and their treatments.

4.1 Effects of personal budgets

People using personal budgets instead of traditional services often report improved outcomes and satisfaction, although older people sometimes see this approach as being burdensome and believe they receive insufficient support to implement it.[31-35] Much of the research comes from social care, including social care in the UK, but there are some international examples.

For example, a randomised trial comparing the USA cash and counselling programme with traditional care found increased access to personal care services, fewer unmet needs, and enhanced satisfaction. Those participating in the scheme were up to 90% more likely than those in the control group to be very satisfied with how they led their lives.[38]

The schemes that are most successful appear to include a supportive signposting or navigation function or assistance with accessing the scheme, managing money, budgeting and accounting, accessing required services and employing and managing staff.[39,40] For instance, the Canadian Individualised Quality of Life project provided 150 people with learning difficulties and their families with personalised planning, support and funding. An evaluation found that having independent planning support or brokerage was particularly valued.[41]

In the Netherlands older people and those with disabilities who have been assessed as needing home care are eligible for a personal budget. Studies suggest that around 80% of eligible people were positive about the services they received, compared with less than 40% using traditional care.[42]

A study by the Dutch Health Care Insurance Council in the early 1990s found that people valued being able to arrange their own care and felt more empowered. There were no significant differences in satisfaction with the quality of the services amongst those receiving and not receiving personal budgets, but personal budget holders had more choice over who provided care, the time at which it was provided and the amount of help provided. A large proportion of people chose to reimburse family members and neighbours. The authors suggested that personal budgets are most effective when the service user is relatively autonomous and able to negotiate an employment relationship with a carer.[43]

Another Dutch study examined personal budgets for home help services. Service users thought that having a personal budget improved their autonomy, motivation, choice, control, independence and quality of life. People thought the quality of the service improved because they were able to specify their own needs and identify appropriate services. A large proportion chose to reimburse family members and neighbours. Instead of prioritising professional qualifications, participants valued the ability to choose their helper and to have flexibility and shared understanding. People thought the quality of the service improved because they were able to specify their own needs and identify appropriate services.

People thought the quality of service improved because they were able to specify their own needs and identify appropriate services.

Many of the budget holders felt less of a burden and their relationships with their carers improved.[44]

Other researchers in the Netherlands conducted in depth interviews with executives, managers, professionals and service user representatives from six long-term care institutions to explore how personal budgets could strengthen the position of service users. The interviewees suggested that the introduction of individual budgets shifted responsibility for budgetary control from the organisational level to the individual level in the caregiver-client relationship. It also put pressure on organisations to have stronger demarcations between regular care and extra 'luxury' care that people might demand. The researchers concluded that personal health budgets can impact on the culture of providing and receiving care. They found this approach encouraged providers to become more client oriented but also helped providers make better distinctions between routine and extra care and thus deal with demanding clients.[45]

Research is also available from Germany. Since 2008, disabled people in Germany have been eligible to receive personal payments to help them better manage their care. Initial pilots suggest that those receiving support feel more empowered.[46]

Beneficiaries of German long-term care insurance living at home can choose to receive cash payments or care-in-kind services.

Those who want cash payments must receive expert advice and 'counselling visits' by a professional nursing service at least twice yearly. Service users and nurses in two regions were surveyed and carers and nurse managers took part in qualitative interviews. Based on this feedback, a family-oriented approach for counselling was tested in 80 homes. The authors suggest that the usefulness and quality of counselling visits varies widely and that a family-oriented approach increased understanding of people's needs amongst professionals, which in turn allowed them to provide better recommendations. This suggests that involving service users and their families at every stage of decision making and planning is useful.[47]

4.2 Summary

Quality of evidence	Medium
Quantity of evidence	Medium

Do personal budgets improve patient-centred care and control?

Yes. International studies suggest that personal budgets can help people feel more empowered and confident about their care. Some similar UK research is also available.[48,49]

5 Value for money

This section explores any evidence about whether personal budgets offer value for money, such as research that costs per patient may be reduced by enabling people to purchase what they judge they need.

5.1 Evaluating personal budgets

It is difficult to evaluate the cost or value for money of personal budgets given the paucity of outcomes, information and accurate costings available.[50]

A review of consumer-directed care in the USA found that costs were not fully accounted for across different evaluations and that a number of studies fail to consider the start up costs of new schemes, the unpaid care and support provided by families or uncompensated out of pocket expenses in traditional care.[51]

A review of personal budgets in social care found that almost all schemes in the EU have underestimated implementation costs, perhaps partly due to unpredicted demand and unmet needs.[52] This means that sometimes evaluations use underestimates when calculating cost effectiveness, making it even more difficult to draw conclusions.

Despite these caveats, there are some positive trends.[53,54] In Germany, it has been suggested that people receiving long-term care spend 50% less with personal budgets than they would with traditional care, and in the Netherlands some suggest spending is 30% less.[55]

A briefing from the Commonwealth Fund describes programmes for personal budgets or other forms of self-directed care in England, Germany, the Netherlands and the US.

Such initiatives have been found to improve satisfaction with services and quality of life and reduce costs compared with services provided by an agency.[56]

In the USA, evaluations have found that 'cash and counselling' initiatives are associated with higher satisfaction, improved access and quality and in some cases, lower overall medical costs. For instance, one US study found that nursing home use reduced by 18% over a three year period.[57,58]

5.2 Summary

Quality of evidence	Low
Quantity of evidence	Low

Do personal budgets provide value or reduce costs per patients?

The impact on costs is unknown.

There is limited information about the costs and value for money of personal budgets. Though some studies have found reductions in health service use and resource costs, analysts suggest that many studies do not fully account for implementation costs or accurately cost comparison groups.

6 Target groups

This section describes whether any research has explored which patient groups benefit the most from personal budgets.

6.1 Benefits for different groups

There have been few studies comparing the benefits of personal budgets for different demographic groups or people with various health conditions. Research has explored the benefits of personal budgets for adults and children with disabilities, adults with mental health issues, people with long-term conditions and people requiring long-term care, amongst others, but there is no comparative information available to suggest that this approach is more effective for some than others.[59,60]

Some research suggests that people from black and minority ethnic groups have low levels of engagement with direct payments and personal budget schemes.[61,62] Social care research in the UK found that more Black and Asian people employed friends or relatives to provide care and that they wanted more support and information from local authorities about how to manage budgets.[63]

Other research in the field of social care in the UK found that the uptake of direct payments by people with physical and learning disabilities was higher in rural or remote areas, but there may be difficulties recruiting and retaining support staff in these areas and overall unit costs may be higher.[64-66]

Personal budget schemes rely heavily on support from family members and informal carers.[67,68] For example 'Home-Care Grants' for older people in Ireland rely on unpaid family care.[69] But research suggests that carers may not always be comfortable with taking on management responsibilities and that it may be important to provide support for carers as part of any personal budgets scheme.[70-73]

6.2 Summary

Quality of evidence	Low
Quantity of evidence	Low

Are personal budgets more effective for some groups?

There is not enough evidence to draw conclusions.

There is limited comparative information internationally about the value of personal budgets for different groups of service users. While some studies have found benefits for those with physical disabilities or mental health issues, and challenges when implementing personal budgets with older people, little else is known about the types of people that this initiative may be most effective for.

7 Social care

This section briefly explores published research about personal budgets and direct payments for social care in the UK.

7.1 Budgets for social care

Research into the operation and impact of self-directed support schemes in the UK includes the National Survey of Direct Payments Policy and Practice (2007), the evaluation of In Control pilot sites (2006–2008), the Individual Budgets Pilot study (2008) and the Individual Budgets outcomes for carers and families.[74-76] Other reviews are also available examining social care budget schemes in more depth.[77-78]

Following on from the adult social care Green Paper, 'Independence, Wellbeing and Choice,' the Putting People First initiative encouraged councils to increase the number of people receiving direct payments and to roll out a system of personal budgets for all users of adult social care between 2008 and 2011. In the long-term it is hoped that all service users will have a personal budget from which to pay for their social care services, apart from in emergencies

For convenience, the section is divided into UK research about direct payments, personal budgets and individual budgets, although it is acknowledged that there is overlap.

7.2 Direct payments

Direct payments occur when people get a cash payout to purchase their own care. Research suggests that a number of factors are important for implementing direct payments in social care in the UK including:[79-84]

- an effective support or signposting mechanism
- providing accessible information to potential recipients
- training and support to improve the knowledge and attitudes of frontline staff and local authority leadership

A comparison of the implementation of direct payments in the four countries of the UK found:

> *The prospects for implementation appeared to be enhanced where there had been long standing user led support for direct payments from the disability community combined with strong political commitment from the purchasing authority. In particular partnerships involving a user led support scheme for direct payments users and a designated fulltime post to champion policy development within the authority appeared to offer the strongest basis for implementation.*[85]

Barriers identified included concern over managing direct payments among carers and service users, staff resistance to direct payments and difficulties regarding the supply of people to work as personal assistants.[86]

In Scotland, research found that social care staff may have narrow ideas about who might be most suitable for direct payments. Staff thought that this initiative would be most beneficial for younger disabled people and this was reflected in uptake rates.[87] In England, the Commission for Social Care Inspection (CSCI) also found that local authority teams were selective about to whom direct payments were promoted.[88,89]

7.3 Personal budgets

Personal budgets in social care are usually managed by organisations or third parties, with the service user providing instructions about what to purchase. Personal social care budgets were evaluated in two studies by the In Control programme. The first evaluation was conducted with six local authorities and 90 people with learning disabilities. The pilot helped improve self determination, support, finances and home and community life.[90]

The second evaluation examined how this approach worked for adults with physical disabilities, sensory disabilities, older people and people with mental health problems. Seventeen local authorities and 196 service users took part. The initiative was associated with improved quality of life, participation in community life, choice and control. People with learning disabilities and physical disabilities were more likely to report improvements than older people.[91]

7.4 Individual budgets

Individual budgets combine funding from adult social care and other sources. Individual budgets were piloted with 959 people in 13 local authorities in England over a six month period.

Around one-third of people were physically disabled, about one-quarter were older people, about one quarter were people with learning disabilities, and around one in 10 had mental health problems.

An evaluation aimed to identify whether individual budgets offered a better way of supporting disabled adults and older people than conventional methods. The evaluation examined experiences and outcomes for service users and carers; the cost effectiveness of individual budgets compared with standard care; organisational implications; how services purchased through individual budgets are commissioned, managed and coordinated; and workforce implications including workload, training and legal and professional issues.

The evaluation of individual budgets published in 2008 found:

- People using individual budgets were more likely to feel in control of their lives than those receiving conventional support.
- People with mental health issues and disabled people were most satisfied with individual budgets. Older people were least satisfied and a substantial proportion saw this as a burden, although take-up rates improved after the evaluation.
- There were significant barriers to integrating funding streams.

The evaluators also suggested that:

> *'Individual budgets have the potential to be more cost effective than standard care and support arrangements. The cost effectiveness advantage looks clearer for some people with mental health problems and younger physically disabled people than for older people or people with learning disabilities. As a whole, the individual budgets group was significantly more likely to report feeling in control of their daily lives and the support they accessed.*[92]

Excluding expenses associated with piloting, the estimated average cost of implementation was £290,000.[93]

Other analyses suggest that individual budgets in social care need careful planning, including preparing staff for changes in funding; clarifying the new roles and responsibilities of community nursing teams; training staff who are employed directly by patients; staff recruitment and retention; and designing evaluation mechanisms which assess quality as well as cost.[94]

7.5 Summary

Quality of evidence	Medium
Quantity of evidence	Medium

Key points

Some large national evaluations have investigated the value of personal budgets in social care in the UK. The findings vary between direct payments, personal budgets and individual budgets.

Whilst implementation was not without challenges, overall the evaluators concluded that this may be an area worthy of further study.

8 Conclusion

8.1 Summary

To date, international evidence about personal budgets in health and social care is somewhat limited and tends to be based on relatively small samples. However, bearing in mind this caveat, the evidence generally suggests that there may be some merit in personal budgets, especially in terms of service user satisfaction and empowerment. The impacts on health outcomes are less clear and the cost effectiveness remains uncertain.

To work well, these programmes need adequate infrastructure, staff training and support for service users and carers.

> *For those less able to manage their support arrangements independently, greater choice and control are only meaningful if they are coupled with help to plan, organise and manage that support.*[95]

Brokerage and signposting support is needed and this may be most successful when it is provided by the voluntary sector or is otherwise independent of the services on offer.

Personal budgets have particularly been found to improve feelings of empowerment amongst those with disabilities and mental health issues. Older people and people with complex needs may need extensive support to help them use personal budgets effectively, particularly where direct payments are used. There is a lack of evidence about how ethnicity or other socio-demographic variables may influence the effectiveness of personal budgets.

Evaluations suggest a number of implementation issues that need to be carefully addressed when considering personal budgets. For instance, there are issues with ensuring that the workforce is safeguarded and that minimum wages and other working conditions apply, especially when people fund family members.

Overall, the findings from UK research and the international literature suggest there is no single most effective model for personal budgets.[96] A comparison of direct payments schemes in the UK, Austria, France, Italy and the Netherlands concluded:

> *There is considerable variation in the way cash for care schemes have developed, but [there] is no single blueprint that can be advocated as without disadvantages, or indeed as the best scheme so far available… we can only stress that these schemes will not, and cannot, offer governments a panacea for the difficult problems they face in developing good quality [health and] social care.*[97]

There is limited empirical research available, and this approach remains in the testing phase. Although some studies are available from the USA, Germany and the Netherlands, the UK also appears to be a leading proponent of this approach. Lessons from personal budgets in social care, where this approach has been tested for some time, suggest that central government leadership is vital, that all schemes internationally have taken time to embed, and that there is a need for strong local leadership and investment in training and support for frontline staff.

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