

The Transition to Personal Budgets for People with Disabilities: A Review of Practice in Specified Jurisdictions

A National Disability Authority Working Paper

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1.0 Key messages

Research undertaken in comparator countries suggests that:

- The evidence base for personal budgets, identified by the search strategy in this report, is limited and so it is difficult to draw strong conclusions about the implementation, management and impact of personal budgets although qualitative findings from service users tend to be positive
- A comprehensive legislative and policy framework is required to ensure that people with physical, sensory, intellectual and mental health disabilities and their carers have choice and control over the funding and services for which they are eligible
- Government, service providers, service users and carers should work together to develop, trial and evaluate different models of personal budgets
- Government involvement and leadership is essential to determine preferred resource allocation models, the parameters of choice and an entitlement-based system across Ireland
- Funding for personal budgets should be based on an objective assessment of people's needs, with the option of individual self-assessment as part of the process
- Government, service provider, service user and carer partnerships should lead on the development of a framework of governance that can balance safety, resources, and the regulation of personal assistants
- Opportunities and forums for sharing innovations and best practice should be promoted
- Appropriately staged and transparent transition arrangements and support need to be established to enable community care providers to prepare for the implementation of personal budgets and develop service options for people with physical, sensory, intellectual and mental health disabilities
- Programmes of personal budgets should be managed and administered in a variety of flexible ways and a range of options should be available that reflects the diverse and changing needs of service users with disabilities and their carers
- The design and delivery of personal budgets requires the adoption of person-centred practice, thinking and planning, promoting service user empowerment, choice and control
- People with disabilities accessing personal budgets should be supported in their decision making through the provision of capacity-building programmes

(including information and education) and the presence of appropriate safeguards to manage risk and promote safety

- Advisor, manager or support-broker services should be available to service users wishing to access personal budgets

2.0 Glossary/definitions

Brokerage

Brokerage refers to the information, support and guidance people may need to enable them to successfully plan, arrange and manage their support and services. Brokerage is usually provided to service users by professionals or through existing organisations and services.

Centres for Independent Living (CIL)

These are usually user-led organisations whose role is to support people with disabilities and their carers to live independently. They may provide a variety of supports ranging from advice, information and advocacy. They may also provide brokerage service to service users for the purpose of accessing support and assistance or organising and managing their own care plans.

Direct payments

In the UK, a direct payment is a cash payment given to eligible service users to enable them to employ personal assistants and to assist them with everyday tasks to facilitate their living independently. The service user is in control and manages the budget allocated to them for their social care and support (not health care). They may choose to employ people themselves or source their care needs from a private or voluntary (not public) sector service organisation. While some service users act as employers, many use an intermediary body such as a Centre for Independent Living to act as an administrator or employer.

Disability

A number of different definitions of disability are used in different policy and legislative instruments, and for statistical and funding purposes. The definition of disability preferred in this review is that provided by Article 1 of the United Nations Convention on the Rights of Persons with Disabilities, namely that 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.

Independent living

Independent living is about supporting people with disabilities to live their lives as full citizens. It involves enabling their choice and control over the way in which their care and support is delivered.

Individual budgets

'Individual budget' was the term used in the UK to describe a series of pilot programmes (now ended) in which funding from a variety of sources was allocated to an individual. They worked in a similar way to a personal budget (see below), but were discontinued.

Individualised funding

Individualised funding refers to types of funding models which offer service users more control over the choice of services and the use of the funding they receive. In some countries individualised funding is known as individualised care packages, personalised budgets, personal budgets, individualised support packages, self-managed care or self-directed funding.

Mental capacity

The ability to make informed decisions is referred to as mental capacity. Some service users may have difficulties making decisions some or all of the time. This could be because they have an intellectual disability, dementia, a mental health difficulty, a brain injury, or a stroke.

Mainstreaming of service provision

Mainstreaming refers to providing people with disabilities access to the same services as those available to the general population. By using mainstream services people with disabilities may experience feel less stigmatised and excluded from public life.

Partnership

Partnership refers to collaboration between agencies across the public, private and voluntary sectors.

Personal assistance

Personal assistance generally means assistance with activities of daily living such as dressing, mobility, or personal care - normally self-directed by the person with a disability. It supports individuals to live independently in the community, and is distinguished from home help which typically involves assistance with housework or shopping. In practice the two roles may overlap.

Personal budget

The term personal budget tends to refer to the total amount of money allocated to a service user to meet their care and support needs following an assessment. It is a form of individualised funding, as defined above, and has a broader meaning than a direct payment, also defined above, although this is one way in which a personal budget may be administered. There are a range of different personal budget models but the central idea behind the concept is to empower individuals to have increased levels of choice and control.

Personalisation

Personalisation involves starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives.

Person-centred planning

Person-centred planning is defined as a way of discovering how a person wants to live their life, and what is required to make that possible. It offers an approach to assessment and care planning designed to assist the service user make plans for his or her future based on their goals and aspirations.

Life course framework

This is a framework for looking at issues that arise for people with disabilities at different stages of their lives and over the life course, e.g. relationships, employment, independence, adulthood, ageing; and at how events earlier in someone's life may influence future events.

Support plan

A support plan is a statement of the supports and services required by a person with disabilities, based on their needs and goals. The service user should be at the centre of the process used to define the support plan, which considers all forms of support; from those available within the family, other informal forms of support to more formal services.

Support

Support differs from care in that it refers to all forms of assistance that enable the service user to realise greater independence and participation in community life. It can however include personal care, social support, as well as: communication or advocacy support; learning, recreation, employment, therapeutic interventions; aids and equipment; and adaptations to the physical environment.

Service user

Service user is a generic term used to describe people who receive, have received, or are eligible to receive, health and social care services, particularly on a long term basis. In some countries terms such as ‘client’ or ‘consumer’ are used to identify recipients of support services.

3.0 Introduction

In 2011 the Irish Government announced its intention to promote ‘choice and voice for service users’ (Government for National Recovery, 2011: 30). It proposed moving a proportion of public spending from a direct service model to one based on personal budgets, with the intention of increasing the level of choice, control and flexibility people with disabilities have over the services and supports they need. Rather than providing fixed budgets to traditional public service providers of social care services, the Government was proposing to place some of these resources in the hands of citizens, to enable them to acquire services better suited to their individual needs.

The main aim of this paper is to provide an overview of the available evidence relevant to the transition to personal budgets for people with disabilities. This involves identifying, describing and comparing programmes of personal budgets across different jurisdictions, and outlining the major reasons for their implementation. This paper gathers, appraises and summarises international evidence; considers and discusses the implications of the research for Irish policy makers, practitioners, service users and carers; and identifies gaps and limitations in the research. In this introductory section the concept of personal budgets will be defined and the political, legislative and policy context will be outlined. In the next section (Section 4) key models of personal budgets will be presented; and in Section 5 the rationale for implementing personal budgets is discussed. Section 6 briefly outlines the methodology used to identify the relevant evidence and the findings are presented in Section 7. Section 8 discusses the implications for Ireland and Section 9 sets out the limitations of the research. Section 10 provides a summary of the review. Detailed methodology and evidence tables are available in a separate appendix report.

3.1. Defining personal budgets

Personal budgets involve an individualised system of funding, based on assessments of need of individuals, and of their changing needs over time (National Disability Authority (NDA), 2010). A personal budget is an amount of funding allocated to a service user to enable them to determine which services they wish to purchase to meet their expressed needs. There are a range of different models but usually needs are assessed by health and social care

professionals, in partnership with the service user. This assessment provides the basis for the personal budget. The idea is that the individual then has some flexibility to meet the needs for which the budget is granted in ways which they choose, giving them greater control over their own social care provision. A personal budget may be paid directly to a service user in the form of a direct payment or paid indirectly through another person, broker or agency or a combination of both (see Brokerage in Glossary).

Personal budget schemes vary considerably but often share common characteristics. For example, the Expert Reference Group on Disability (2011: 15) reported that supports usually

“include assistance provided by others, whether in the form of personal care, communication or advocacy support, learning support, therapeutic interventions, aids and equipment, adaptations to the physical environment, and so on. Individualised supports are characterised as being primarily:

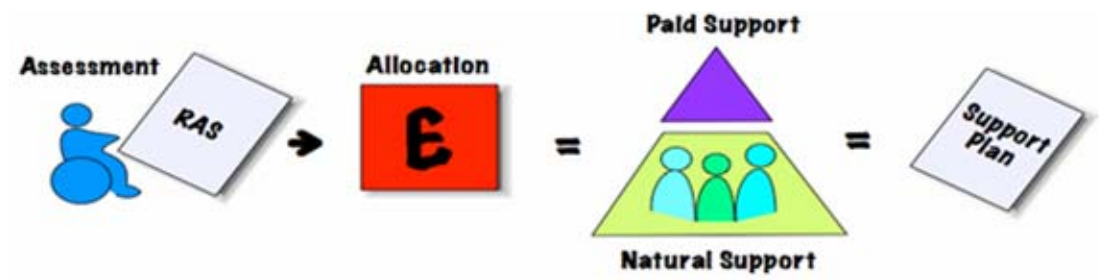
- determined by the person (in collaboration with their family/advocate as required and in consultation with an independent assessor) not the service provider or other experts
- directed by the person (with their family/advocate as required)
- provided on a one-to-one basis to the person and not in group settings (unless that is the specific choice of the person and a natural group activity, such as a team sport)
- flexible and responsive, adapting to the person’s changing needs and wishes;
- encompassing a wide range of sources and types of support so that very specific needs and wishes can be met
- not limited by what a single service provider can provide
- having a high degree of specificity.

Provision that is expressed in terms of residential, day or respite does not capture the specific nature of an individual’s support needs”.

In principle personal budgets can be used irrespective of the person’s age (e.g. older adults, working aged adults, young adults, or children), and by individuals with a wide variety of disabilities, including illness, chronic health conditions, intellectual disability, mental health conditions, sensory impairment, and physical disability, but their availability in other countries is sometimes limited to certain age groups and/or disabilities. The payment of a personal budget is typically characterised by an amount of funding allocated on the basis of a resource allocation system (RAS). The funding can be provided as a voucher for the purchase of services, paid directly to the disabled person or to someone in their

immediate network of friends or family, or to an allocated broker, representative or agency (Glendenning, 2008). The implementation of personal budgets aims to promote personal responsibility, independence, capability and resilience through the delivery of cost effective and innovative services chosen by the service user. Personal budgets mean that "money follows the person's needs" as illustrated in the Figure 1, developed by the *In Control* charity that has piloted various forms of self-directed support in England.

Figure 1: Stages involved in the provision of a personal budget



In Control (2011) identified seven steps to being in control of your own support as

1. set personal budget
2. plan support
3. agree plan
4. control personal budget
5. organise support (both paid and natural support)
6. live life
7. review

3.2. The international context

The Irish government's commitment to ensuring that people with disabilities have greater control over the provision of their support and care services is in keeping with international human rights standards. The principle of self-determination for all people is enshrined in the Universal Declaration of Human Rights. The Convention on the Rights of Persons with Disabilities, adopted by the United Nations General Assembly (2006), included the following general principles: 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices and independences of persons' (Article 3).

The Irish Government can learn from countries further down the road of implementing personal budgets, such as the United Kingdom, the USA, Canada, Australia and the Netherlands (which introduced personal budgets in 1995). Most

countries are still developing and evaluating a range of programmes and models appropriate to their cultural, political and legislative context.

Internationally there is a variety of funding models for the provision of personal budgets, such as ‘direct payments’ in the United Kingdom (Rabbie et al., 2009; Spandler and Vick 2006;), ‘consumer directed care’ or ‘self-directed care’ in states of Australia (Fisher et. al. 2010), and ‘cash and counselling schemes’ in the USA (Dale and Brown, 2006). A range of models has been generated, including, at the one end, large scale national programmes such as the Netherlands model with its links to the national insurance system, and at other end, regional or small scale community based programmes, such as those being developed in states and provinces of Australia and Canada. Later in this section we provide examples of evaluated programmes. Issues around personal payments have generated considerable debate and discussion amongst people with disabilities, professionals, politicians, policy makers and academics (Scourfield, 2005). It is complex to critically appraise the range of individualised funding models that are in use or have been evaluated.

Key jurisdictions were selected to illustrate and compare a range of models of personal budget frameworks. The United Kingdom (including England and Wales, Scotland, Northern Ireland), the United States of America (Washington, Arkansas), Canada (Ontario) and the Netherlands were included because they have personal budget programmes in place. Australia was included because states such as Victoria and Western Australia are exploring innovative approaches to individualised budgets. Further details of the methodology and evidence tables of the included studies are provided in the appendices. In addition to the 23 country specific articles in the Table I below, two review reports produced by the Social Care Institute of Excellence (SCIE) (2009) and the Health Foundation (2010) were also included and are summarised in the evidence tables.

Table I: Jurisdictions, reviews and descriptor terms

Jurisdiction	Studies/Reports	Sample size	Descriptor Terms
UK	Alzheimer’s Scotland (2008)	12; 10; 28	Personal Budgets Individual Budgets
	Fernandez et al. (2007) (England)	Not applicable (na)	
	Maglajlic et al. (2010) (England)	10; 10; 10	
	Stainton et al. (2009) (Wales)	23; 88	
	Glasby et al. (2009)	na	
	Jones et al. (2011)	20	
	Pearson (2004) (Scotland)	na	

Jurisdiction	Studies/Reports	Sample size	Descriptor Terms
	Riddell et al. (2006)	21; 102	
	Rabiee et al. (2009)	14	
	Spandler and Vick (2006) (England)	27	
	Glendinning et al. (2008)	959	
	Scourfield (2005)	na	
Ireland	Timonen et al. (2006)		Cash for care, personal budgets
Netherlands	Kremer (2006)	na	Person-centred budget
	van Ginneken et al. (2012)	Na	
Australia	Laragy and Ottmann (2011)	5-8; 9	Self-Directed Funding, Consumer - directed Care Local Area Co-ordination Program
	Fisher et al. (2010)	132; 32; 8	
USA	Cook et al. (2008) (Arkansas)	106	Consumer Directed Care/Support Cash and Counselling
	Dale and Brown (2006)	2,008	
	Foster et al. (2003) (Arkansas)	1,739	
	Sikma and Young (2003)	125; 69; 29; 30; 30; 24	
	Rosenberg et al. (2005) (Wisconsin)	Na	
Canada	Spalding et al. 2006	16	Self-managed Care Individualised funding Program Support for Interdependent living

3.3. The national context

Within the Republic of Ireland there has been a growing emphasis in policy and legislation for a more personalised approach to meeting the needs of people with disabilities. This is a central theme in the report of the Department of Health's (2012) Value for Money and Policy Review of Disability Services¹ and of the Expert Reference Group which completed the Policy Review of Disability Services (2011) which informed the Department of Health's report.²

The Expert Reference Group recommended that “the necessary actions be taken to put in place a system of individualised funding for people with disabilities. This system should include a range of options for the administration of individualised funding and should take into account the required processes for individualised resource allocation” (p. 150).

The Value for Money and Policy Review concluded “it would not be advisable to move to a fully individualised budgeting system until the necessary availability of alternative service options had been properly, piloted, tested and sufficiently established so as to avoid the creation of a vacuum in service quality. However, the balance and emphasis needs to shift firmly and comprehensively towards these new models of individualised supports once (i) sufficient analysis of their benefits is carried out in the Irish context and (ii) adequate financial management, resource allocation and governance structures are in place to ensure their long-term viability.” (p. 172).

3.4. Rationale for reform

Timonen et al. (2006) note that, internationally, the rationale for welfare reform reflects a, sometimes conflictual, mix of social justice and economic objectives, including:

- increasing freedom of choice, independence and autonomy for care recipients
- compensation for gaps in existing services
- the creation of jobs in personal care services
- efficiency gains or cost savings through reduced overheads and increased competition between providers
- the shift of care preferences and use from institutional to domiciliary or home care

(Timonen et al., 2006).

¹ http://www.dohc.ie/publications/pdf/VFM_Disability_Services_Programme_2012.pdf?direct=1

² http://www.dohc.ie/publications/disability_policy_review.html

Further to Timonen et al.'s (2006) first point, personal budgets have been promoted as the key to the expression and realisation of service users' fundamental human right to have the support necessary to exercise self-determination, choice, independence and control (Fernandez et al. 2007). This reflects a wider personalisation agenda in social care across western countries. The concept of personalisation developed from the social model of disability and the philosophy of independent living, and underpins the rationale for personal budgets. According to Barnes (2007) the philosophy of independent living in disability services is shaped by four assumptions. These include:

- that all human life, regardless of the nature, complexity and/or severity of impairment, is of equal worth
- that anyone, whatever the nature, complexity and/or severity of their impairment, has the capacity to make choices and should be enabled to make those choices
- that people who are disabled by societal responses to any form of impairment, physical, sensory or cognitive, have the right to exercise control over their lives
- that people with perceived impairments and labelled disabled have the right to participate fully in all areas – economic, political and cultural - of mainstream community living on a par with non-disabled peers

(Barnes 2007:36)

4.0 Meeting the challenge

A consultation by the Health Service Executive, conducted in 2009, revealed that people with disabilities in Ireland want “flexible supports to suit individual needs... to use local services – do ordinary things in ordinary places” ... [with more opportunities for families to] “play their part in supporting their family member”.³ Service users expressed dissatisfaction with the limited amount of choice they had over the service received from service providers, with the majority wanting different things from different providers. Most respondents were dissatisfied with the amount of control and independence they had.

The challenge facing the Government is how best to move to a model of personal budgets, faced with the growing number of people with disabilities and of older people, coupled with increased complexity of needs, together with concerns about both quality and cost-effectiveness.

³ Health Service Executive (2009) p.3

In order to understand the options available to the Government in the transition to personal budgets, different models and examples from comparator countries are presented and reviewed.

4.1. International models of personal budgets

As indicated above, there is no single approach to the provision of personal budgets; rather, there is a range of models of delivery that differ in the levels of choice and control vested in services users, professionals, agency providers and public funders. Programmes vary considerably in areas such as functional and financial eligibility, services covered, benefit limits, hiring restrictions, administrative structures and funding sources. This, in turn, affects the level of flexibility and creativity available to meet the needs of individual service users in local contexts. This review has identified three main approaches to the provision of personal budgets.

Professionally monitored model

In this model, service users receive mandated guidance from care managers or co-ordinators, who are also responsible for monitoring services over time according to an approved care plan. Health professionals such as social workers and nurses tend to play a key role in the assessment and care planning processes.

Professionally assisted model

Here, service users receive assistance from care managers/co-ordinators/brokers to access funding and co-ordinate support and care. The professional/agency/broker may also assist with the determination of decisions regarding hiring, scheduling, supervision and terminating of workers.

Service user directed model

In the service user directed model, service users receive periodic cash allocations based on an assessment of needs and subsequent care plan. They have wide discretion with respect to purchasing virtually any services or goods they deem appropriate to meet their needs and the objectives of the care plan. Optional independent professional counselling and advice may be available, separately from the funding, to assist the service user.

The different approaches are best understood along a continuum involving the relative level of control between professionals and service users, with the professionally monitored models of service delivery at one end and the service user directed model at the other.

The three approaches to personal budgets are described below using examples from the review of comparator countries.

Example: Professionally monitored model

Direct Payments UK (England, Scotland, Wales and Northern Ireland)

Context and legislation: The Community Care (Direct Payments) Act 1996 made provision for user-controlled purchasing for people with physical disabilities, intellectual disabilities, mental health problems and older people (Fernandez et al., 2007).

Operationalisation: Local councils in England and Wales and Health and Social Care Trusts in Northern Ireland are required to make available personal budgets in the form of direct payments to eligible service users.

Level of professional/agency involvement: Most direct payment programmes involve a case manager (usually a social worker) for the development and monitoring of care plans and the authorisation of provider payments (Mahoney et al., 2004). Following an assessment, eligible service users are provided with a budget. This may be in the form of cash or a voucher of a value which should be sufficient to meet the assessed needs. The hours of care needed are identified and determined by a resource allocation model (RAS). While still choosing how their care needs are met and by whom, service users can opt to leave local authorities with the responsibility to commission the services, or some combination of this and a direct payment.

Level of service user control: Individual recipients of direct payments should know how much money they are to receive and how the much relevant services cost. In some areas brokerage services are available to guide people on spending their budgets and sourcing services.

Example: Professionally assisted model

Local Area Coordination and Direct Consumer Funding, Western Australia

Context and legislation: In Western Australia a form of personal budget was introduced in 1988 with the Local Area Coordination charter and programme which administers a system of Direct Consumer Funding in the federal state of Western Australia.

Operationalisation: Under the Western Australian state legislation, the Local Area Coordination programme has a clear charter to support people with physical, intellectual and sensory disabilities, and those with mental health problems (and their families) to identify their own needs, determine their preferred services, and control the required resources to the extent they desire.

Professional/agency involvement: Local area coordinators provide information, assist with support networks and help people purchase their own

supports through direct consumer funding. Coordinators are given time to get to know service users' resources, strengths and needs. Funding is provided in two ways, tied or untied. Tied funding requires a detailed plan involving formal and informal supports and is usually longer term. Untied funding comprises one off funding in an emergency and is provided at the discretion of the coordinator. Funding covers respite, personal support, and support for education, employment, leisure, employment, equipment and accommodation. The role and involvement of the coordinator has proven to be particularly effective in helping service users purchase support in flexible and creative ways in rural and remote areas where no formal service system existed.

Service user control: Funding was initially controlled by the coordinator, but direct funding to individuals and families was subsequently introduced (Laragy and Ottmann, 2011).

Example: Service user directed model

Persoonsgeboindenbudget (Person Centred Budget), The Netherlands (Kremer, 2006)

Context and legislation: In 1995 the Netherlands instituted a programme based on social insurance in which people could choose to receive a personal budget rather than services.

Operationalisation: Cash payments are financed through the country's social health insurance programme which enables clients to purchase services and support from the provider of their choice, including informal carers or agencies from regulated or private markets. Payments are determined by a formula and paid by the Social Insurance Bank. There are limitations on the hours of nursing care that can be provided. The majority of budget holders have opted for the employment of family members (Kremer, 2007).

Agency/professional involvement: Fiscal agents are available (for a fee) to assist people to make best use of their budgets. When used, the independent fiscal agent assumes responsibility for paying individual home care workers.

Service user control: Entitlement is open to any person of any age who requires assistance with independent living. Children and service users with cognitive impairments must have a surrogate decision-maker, in order to be eligible to participate.

Summary

These examples demonstrate the considerable variation in the way personal budgets have developed across jurisdictions. Each has advantages and disadvantages. For example, professionally monitored approaches may enhance

accountability but may also be more restrictive and intrusive for service users. Service user directed programmes offer considerable choice and control, but may place undue administrative pressure on the service user, in the absence of the support of brokers or agencies such as Independent Living Centres. The following table summarises the advantages and disadvantages of the three approaches to the operationalisation of personal budgets.

Table 2: Strengths and limitations of personal budget models

Professionally monitored	Professionally assisted	Service user directed
Strengths: assessment, clear eligibility and entitlement, advice and support, monitoring, accountability, quality control	Strengths: person-centred, capacity building (family, community), access to mainstream services, advocacy	Strengths: choice, control, independence, flexibility, access to support and care services
Limitations: restrictive, intrusive, less flexible, level of professional involvement, limited access to different sources of funding	Limitations: availability of professional services and resources, extent of professional involvement	Limitations: fiscal accountability, support, advocacy, mental capacity and ability, responsiveness of care professionals and market, quality control

Conclusion

The transition to personal budgets presents complex financial, political and practical issues. It cannot be assumed that one model of personal budgets will provide the solution for all service users. Service users need a range of options to meet their changing needs.

5.0 Importance of personal budgets

In this section we summarise the importance of personal budgets to children and adults with disabilities in the current Irish context.

5.1. Service users

One of the claims made for personal budgets is they facilitate opportunities for personal development and greater independence for people with disabilities through increased responsibility, flexibility and choice (Egan, 2008). Evans (1995) claims that personal budgets have pioneered independent living, enabling people with disabilities to move out of institutions, to have more control and choice over their lives, and have contributed to a better quality of life with more

flexibility and satisfaction and real empowerment. In a large (n=1,114) survey of people using personal budgets in the UK, Hatton and Waters (2011), reported positive experiences of the impact of personal budgets, although more mixed responses about the processes involved.

However, there are concerns that complicated personal budget schemes can reduce control and oversight for some service user groups (Ungerson, 2004). Some UK user groups have criticised government plans to introduce personal budgets into healthcare as being too restrictive and bureaucratic in administration. Galpin and Bates (2009) point out that there are “winners and losers” in every model of social care provision, with service users who lack the essential attributes and support to make rational and strategic choices, being less able to benefit from personal budgets compared to other groups. Those without the ability or capacity to manage personal budgets can be excluded from access to this type of funding, unless support (such as advocacy, financial assistance and protective policy/legislation) is in place to facilitate their participation. Personal budgets provide opportunities to enable people with significant cognitive disabilities to exercise their preferences, but they may also present unique challenges for supporting and communicating decision making.

5.2. Issues for service providers

The successful introduction of personal budgets depends on the positive response of existing disability services to adopt new care philosophies. This requires not only moving from professionally driven (case management) to person-centred (service user directed) models of provision, but also the emergence of new types of services and categories of service providers that can respond to the demands of service users. In order to take control of budgets, service users may require a range of advocacy, brokerage, planning, administrative and independent living support services, depending on their individual needs.

The introduction of personal budgets can have the effect of helping to create new services and means of support, effectively breaking down the near monopoly of existing home-care organisations (Timonen et al. 2006). The introduction of personal budgets can increase the demand for personal assistants (Spandler, 2004), a human resource which may or may not exist in local communities. In some cases personal assistants may be drawn from informal support networks such as family members and significant others, but the use of paid, informal personal carers has implications for the standard of care provided and raises issues of regulation and accountability, which are further discussed in Section 7.

Existing service providers may find the introduction of new market models and the prospect of having to ‘sell’ their care services somewhat challenging. For example, service providers in Australia have criticised their Government for

wanting control of agencies, but distancing themselves from the risks and responsibilities of provision (Aged and Community Services, 2008). The New South Wales Council of Social Services (2006) voiced concerns over the introduction of complex funding and contractual arrangements, increased level of accountability to government and outcomes-based funding which has capacity to skew the client base (e.g. 'cherry picking' or prioritisation of service users with the lowest levels of need rather than those with the most complex and expensive needs). Promoting the 'growth' of new support services and a flexible care workforce involves developing a culture of collaboration between government and service providers.

5.3. Issues for policy makers and commissioners

In Ireland, the Health Services Executive currently holds budgetary responsibility for services for people with disabilities. Public bodies are obliged to ensure that public funds are fully accounted for, and used by people with disabilities and organisations for the purposes intended (Egan, 2008). The introduction of personal budgets is thought, by some, to have the potential to increase opportunities for the misuse of funding or budget allocation difficulties. However, it also has the potential for cost saving and greater flexibility to respond to the needs of people with disabilities, and to prevent inappropriate institutionalisation and hospital admission.

6.0 Methodology

For this review we have carried out a Rapid Evidence Assessment (REA). REAs provide more thorough syntheses than narrative reviews, and are valuable where a robust synthesis of evidence is required, but the time or resources for a full systematic review are not available. The reviewers develop and then specify search strategies in collaboration with clients and other key stakeholders. Each study is quality assessed using standardised instruments.

We searched a number of databases and websites to identify a range of different studies of relevance to this review:

- Medical databases: Cochrane Library, Embase, Medline, PsycInfo
- Social science databases: Campbell Library, SocIndex, Web of Science
- Economics databases: CRD (NHS EED), EconLit

We also searched a number of websites for additional relevant reports or documents. These included:

- The University of York Social Policy Research Unit www.york.ac.uk/inst/spru/
- The Commonwealth Fund www.commonwealthfund.org
- John Rylands University Library www.manchester.ac.uk

- University of Bristol www.bristol.ac.uk
- Social Care Institute for Excellence www.scie.org.uk
- Audit Commission www.audit-commission.gov.uk
- NHS Confederation www.nhsconfed.org
- Health Foundation www.health.org.uk
- University of Leeds www.leeds.ac.uk
- Scottish Government www.scotland.gov.uk
- Third Sector Research Centre www.tsrc.ac.uk
- In Control www.in-control.org.uk
- Local Government for Improvement and Development www.idea.gov.uk
- Department of Health www.personalhealthbudgets.dh.gov.uk
- Hampshire County Council www.hants.gov.uk
- Acevo www.acevo.org.uk
- Stockport Council www.stockport.gov.uk

All studies identified as potentially relevant were imported into a database and duplicate studies removed. Full papers were obtained for all, those studies that were judged by two reviewers to be potentially relevant to the topic. Only studies that provided directly relevant data were included, but if an excluded study or report provided important opinions, discussion and/or contextual information, it was used to inform the earlier sections of the report and some of the considerations of the implications of the included studies.

Relevant data from each included study were summarised into a structured table, and these are reported in Appendix 2. Each included study was assessed for overall methodological quality and given a high, mid or low quality score. The details of the quality assessment are reported in Appendix 1 (Appendices available separately on request).

7.0 Findings

This report aimed to identify evidence of good practice in relation to personal budgets, the challenges they present, and how these might be overcome. It sought to consider the views of key stakeholders on the experience of personal budgets, and to identify key lessons for effective development and implementation.

This section begins with four tables, summarising the findings from the evidence in relation to the factors that facilitate the uptake of personal budgets by service users (Table 3); what research studies say about the impact of the introduction of personal budgets on service users, both positive and negative (Table 4); the factors that can facilitate or impede the implementation of personal budgets (Table 5) and the range of uses made of personal budgets (Table 6).

We then consider what the evidence has to say in relation to a number of critical questions, organised thematically as follows:

- Inclusion and self-determination
- What are the outcomes for service users and carers?
- Do personal budgets enhance equality and diversity?
- Do personal budgets improve health outcomes?
- Efficiency and effectiveness
- Are personal budgets cost-effective?
- What are the perceptions of front-line staff?
- What are the implications of personal assistance?
- What is the role of support and brokerage services?

We conclude the section with a discussion of the implications of the evidence for the development of personal budgets in Ireland.

7.1. Summary of findings by theme

Service user uptake of personal budgets

The review identifies significant variations in the uptake of personal budgets by service users. For example, Alzheimer Scotland (2011) identified barriers that limit the wider implementation of personal budgets for service users with dementia and their carers across 28 local authorities. It recommended a number of changes such as: better information and support, clear policy and guidance from central governments and a greater focus on outcomes. Samuel (2012) reports that, in England in 2010-11: “29% of [eligible] older people were on personal budgets, compared with 41% of working-age adults with a learning disability and 35% of physically disabled adults of working-age. However, the uptake figure was even lower for people with mental health problems of working-age, at 9%” (p. 1). The following table outlines factors help facilitate service user’s access to personal budgets and those that act as barriers or limit their access.

Table 3: Factors facilitating service user uptake

Factors facilitating uptake	Factors limiting uptake
affluence and ability of service user effective leadership staff knowledge and positive attitude commitment to person centred approaches good quality information staff training on-going support capacity to spread costs generous packages recipients can decide their level of control reduced professional involvement in family life flexible use of budgets support with planning and getting the best services. local authorities check and monitor care plans strong disability advocacy base policy development appropriate infrastructure	determining the mental capacity of service user ⁴ need for an appropriate person to manage budget time consuming to set up too much responsibility feelings of isolation attitude of staff anti-market attitudes and culture lack of information lack of promotion financial constraints in some local authorities direct payment legislation emerged after cuts made local authority restructuring direct payment packages too small needed more support than was available eligibility criteria limited difficulties recruiting workers managed care was felt to be more cost-effective health and safety issues

Service user outcomes

Studies tended to report largely positive service user outcomes from the provision of personal budgets. Benefits ranged from increased choice, control and independence to improved health and wellbeing. For example, in a small study of five families, Laragy and Ottmann (2011) reported increased self-esteem of families, which they attributed to the fact that families did not have continually to need approval from a case manager for their support arrangements. Some studies also evidenced negative outcomes. For example, Fernandez et al. (2007) used various databases to explore the demand, supply and uptake issues relevant to

⁴ a 2011 Court judgment (re PF and the South Eastern Health and Social Care Trust) in Northern Ireland concluded that the current legislation in that jurisdiction does not permit the making of direct payments for care to a person who does not have the mental capacity to consent to the making of such an arrangement.

direct payments. They reported that some older service users and their carers, experienced stress as a result of the administrative and bureaucratic requirements involved.

Overall, different user groups were likely to report different outcomes. From their survey of people using personal budgets in the UK (n=1,114), Hatton and Waters (2011) reported that: “older adults tend to report less positive outcomes than other social care need groups in six out of the 14 outcome domains. However...these differences are ones of degree (older adults are more likely to record personal budgets as making no difference; they are not more likely to record personal budgets as making things worse). It is also important to note that less positive outcomes for older adults may not be a function of age as such, but could reflect the fact that older adults are less likely to use personal budgets in ways that are associated with positive outcomes. For example, older adults are less likely to use direct payments, less likely to know how their personal budget was managed, and more likely to have a personal budget managed by the council – all these factors are associated with less positive outcomes” (p. 26).

The Health Foundation’s summary of the relevant research (2010: 3) concluded: “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”.

Table 4: Service user outcomes

Benefits attributed to personal budgets	Disadvantages attributed to personal budgets
<p>support suited to the personal circumstances of the family</p> <p>better responses to changing needs</p> <p>more choice and control over how support is provided</p> <p>employ a carer already known</p> <p>quality of life at home improved</p> <p>greater contribution to the community</p> <p>improved personal dignity</p> <p>better health</p> <p>better economic wellbeing</p> <p>more safe and secure at home</p> <p>greater satisfaction</p> <p>better value for money</p> <p>easy to manage once set up</p>	<p>Lower psychological wellbeing in older people</p> <p>people with fluctuating conditions reported problems with self-assessment and planning</p> <p>difficulties completing the assessment process</p> <p>concerns that giving wrong answers could impact on the level of personal budget</p> <p>people without experience of managing struggle to cope with responsibilities</p> <p>those with intellectual disabilities need an advocate to help fill out forms and assess</p> <p>difficulties recruiting personal</p>

Benefits attributed to personal budgets	Disadvantages attributed to personal budgets
reduced nursing facility use have paid employment have vocational skills training take part in volunteer activities enrol in postsecondary education or general equivalency diploma classes less likely to report poor performance of caregivers improved medication management	assistants initial set-up time consuming care-givers suffer emotional stress, due to burnout care-givers' occupational risks of injury case managers need more clarity in their role in assessing fluctuating abilities to self-direct

Implementation of personal budgets

The efficient and effective implementation of personal budgets appears to depend on a range of issues that may either facilitate or discourage the transition process (Riddell et al. 2006; Pearson 2010). The findings of this review illustrate the scope of change that needs to take place at service user/family (micro), service provider (mezzo) and legislative, policy and cultural (macro) levels for the implementation of personal budget programmes (Laragy and Ottmann, 2011). Key issues - such as the shift in the philosophy and provision of care (Spandler and Vick, 2006; Scourfield, 2005) and the availability of a personal assistance (Riddall et al., 2006) - are highlighted in the table below.

Table 5: Factors impacting on the implementation of personal budgets

Factors facilitating the implementation of personal budgets	Factors hindering the implementation of personal budgets
effective personal budgets support scheme; training and support for front line staff; leadership; positive attitude to personal budgets among staff; national legislation, policy and guidance; accessible information on personal budgets for service users and carers; demand from service users and carers for personal budgets; availability of people to work as personal assistants; targeted support within the personal budgets support service to promote	difficulties with the availability of people to work as personal assistants; concern about managing direct payments among service users and carers; resistance to direct payments among staff; competing priorities for policy implementation; inadequate training and support for front line staff; underdeveloped direct payments support scheme; lack of demand from service users and

Factors facilitating the implementation of personal budgets	Factors hindering the implementation of personal budgets
personal budgets; local political support for personal budgets; central government performance monitoring; strong local voluntary sector; personal budgets developments/innovations awards; flexibility of commissioning strategy; inspection and regulation of services; ring-fenced budget for personal budgets; support from a National Centre for Independent Living; support of public sector trade unions	carers for direct payments; incongruence of direct payments policy with other local authority duties; inflexibility of commissioning strategy; weak local voluntary sector; insufficient leadership; lack of targeted support within the direct payments support; national legislation, policy and guidance; lack of ring-fenced budget for direct payments; lack of local political support for direct payments; lack of support from the National Centre for Independent Living

Uses and application of personal budgets

Personal budgets provide increased flexibility and can offer access to a wide range of support services. These services can be provided by a range of service providers, or can be provided by the employment of family members, and involvement in mainstream social and recreational and employment opportunities that have not been traditionally available to service users. The difference between the provision of care and support services, and the ways in which personal budgets can be used to meet the need of service users, are outlined in the following table.

Table 6: Uses of personal budgets

Care	Support
personal care purchase services from a service provider respite equipment and modifications	personal assistants social/recreational activities domestic tasks employment advocacy and administrative services

Note that personal budgets tend to be used for social care and support, not for health care services, although the distinction can be problematic and there are variations across models.

7.2. Thematic summary of findings by critical questions

The Government's rationale for reform reflects a commitment both to the promotion of the inclusion and self-determination of people with disabilities, and the creation of a cost effective, accountable and responsive system of service delivery. The findings are discussed in relation to a series of critical questions relating to each of these aims.

7.2.1 Inclusion and self determination

What are the outcomes for service users and carers?

Service users' responses to the introduction of personal budgets vary according to scheme and service user group. However, reactions are largely favourable to the idea of personal budgets as an option, given the right kind and level of information and support. The UK National Personal Budget Survey (Hatton and Waters, 2011) found that service users reported more positive outcomes if they were themselves managing their personal budget, rather than if the budget was professionally managed or monitored. Service users accessing self-directed support, compared to current services, are generally more likely to report improved outcomes and satisfaction, although there have been exceptions regarding older people (Poll and Duffy, 2008). Young and Sikma's (2003) US study reported high levels of satisfaction with personalised budgets, emphasising freedom and the opportunity to take control of important aspects of life and daily care. Glendinning et al. (2008)'s evaluation of the Individual Budgets pilot in England reported that generally service users reported improvements in quality of life, care and control although there were differences between groups as will be further discussed below.

Likewise, Laragy and Ottmann's (2011) small scale Australian study reported that the self-esteem of the five participant families was enhanced because they were no longer reliant on a case manager. However, the families in this study also reported a need for more information and support than was available. Ensuring service users are well informed of their financial allocations and providing them with adequate support to implement care plans and services were identified as critical factors in this study.

Overall, the evidence suggests that personal budgets outperform traditional services in meeting service users' needs. A large survey of over 1,700 people in the USA found that the ability to employ paid personal assistants was highly valued by service users (Foster et al. 2003). In an Australian study (Victorian Government, 2010), the different forms of employment options available to

service users included hiring through a company, association or cooperative; or directly. Different employment models suit individuals at different points in time. Services users require knowledge and information to support informed decisions as to what model suits them at a particular time, and to support the transition between arrangements as required or desired.

The Alzheimer Scotland (2011) small-scale study (12 carers, 10 social workers and 28 Local Authorities) found that payments were used for personal care, social/recreational activities, domestic tasks and respite. In this study, personal budget recipients used their payments more often to employ personal assistants than to purchase services. It also indicated perceived benefits to be: tailored outcomes; improved value for money; improved quality of care; and improved health outcomes. Considerable work has also been done by **In Control** (Hatton and Waters, 2011) on the impact of personal budgets for carers. Most carers reported a positive impact of the personal budgets on their quality of life and physical and mental health. Carers reported that the receipt of personal budgets by the person they cared for had no impact on their own capacity to get and keep a paid job. However, they did express concerns about other aspects of the personal budget process - particularly the stress and worry associated with personal budgets. For the family carers of older service users, the impact of personal budgets was less positive. The impact on carers appears to be linked to factors such as whether the carer is living in the same house as the service user, and how much care and support the carer is providing.

Adequate information and support appear to be the key to positive outcomes for service users managing their own personal budgets.

Are issues of equality and diversity addressed?

There has been an assumption that personal budgets will improve choice and control for all people with disabilities (Audit Commission, 2007). However, recent UK research has failed to yield significant findings on the implications of individual budget schemes for members of minority groups (SCIE, 2008). There is a suggestion that, without care, the introduction of personal budgets may result in inequalities such as a two-tiered system of service provision, in which some (the majority community) are able to avail of personal budgets; and others (minority groups) are not (Galpin and Bates, 2009; Bloche, 2000).

The evidence suggests that different service user groups report different outcomes. Glendinning et al., (2008: 2) reported that “mental health service users reported a significantly higher quality of life; adults with physical disabilities reported receiving higher-quality care; people with learning disabilities were more likely to feel they had control over their daily lives; and older people reported

lower psychological wellbeing, possibly because they felt that the processes of planning and managing their own support were burdens”.

The up-take of personal budgets in the UK remains highly variable between the four different countries, across local authorities within those countries, and between different groups of social care service users. For example, rates of uptake are highest in England and lowest in Northern Ireland, and the up-take of direct payments by people with physical and intellectual disabilities is highest in areas with lower population density (Fernandez et al., 2007). People with physical and sensory impairments have had consistently higher rates of up-take, while older people, people with intellectual disabilities and people with mental health problems have had much lower average take-up rates (Riddell et al., 2005; Priestley et al., 2006; Davey et al., 2007).

In a national Australian study (Fisher et al., 2010), it was found that individual funding is more likely to be used by people of working age with low support needs, by male and non-Indigenous service users, by people with a single impairment, and by people across all disabilities without informal care networks. Specific issues of diversity and differing needs are summarised below.

Older people and people with complex needs require greater time and support to help them get the most from personal budget schemes, particularly the cash direct payment option. Alzheimer Scotland (2011) identified that the main barriers to take up of personal budgets for older people included the need for an appropriate person to manage the direct payment as the illness (dementia) progressed. Many of those interviewed acknowledged the issue of not being able to get a direct payment unless the person with dementia had the capacity to consent or the family carer had appropriate legal powers in place.

There are considerable barriers to uptake for people with mental health problems. Not all local authorities extend personal budget schemes to all health services. UK research suggests that some practitioners may perceive some groups as ‘risky’, particularly people with mental health problems, and limit their access to personal budgets (Taylor, 2008). One study found that people with mental health problems were more likely to receive a personal budget if they had family or a ‘significant other’ to help manage it (Spandler and Vick, 2001).

There is relatively little evidence from which to draw conclusions about the impact of personal budgets for families with children with disabilities. Laragy and Ottmann’s (2011) small scale (5 families) study of personal budgets for families caring for children with disabilities reported high satisfaction with parents’ self-management of their funds. Overall improvements were reported in their level of control, which led to more appropriate activities and enhanced social participation of the disabled child. The self-esteem of families was enhanced

because they did not have to continually seek approval from a case manager. However, the families felt they needed more information and support than was available to make decisions. A significant finding was that families' feelings of isolation grew with less support from professionals, despite peer support from other families.

One of the challenges to the implementation of personal budgets is that some models appear to work well for some categories of service users and not for others. It is therefore important to attempt to address these different needs, whilst preventing the fragmentation of service provision. Service providers need support to negotiate personal budgets because of possible barriers including complexity of needs, geographic distance, racial and ethnic bias, cultural barriers, mental capacity issues and discriminatory attitudes. Information and support, clear policy guidance, legislation and advice on decision making capacity are all key issues for the equitable provision of personal budgets.

Will personal budgets improve health outcomes?

Findings from the evaluation of Cash and Counselling schemes in the USA suggest that people in receipt of a personal budget may be more likely to use health services (Robert Johnson Wood Foundation, 2007). This could be due to the improved identification of health needs arising from the assessment process and the greater availability of funding which, in the context of the USA, may address some of the financial barriers to accessing health care. In the same study, recipients employing their own personal assistants were more likely to experience positive health outcomes, such as a reduction in falls and bedsores due to personal care provided. Alakeson (2008), in a discussion of the USA and UK systems, compared self-directed care with the traditional system and found that people using the former make greater use of routine services, and that there is a shift towards prevention and early intervention. This can lead to efficiency gains by avoiding costly acute interventions. The Australian Government's (Fisher et al., 2010) evaluation found that most service users using individual funding experienced personal wellbeing and physical and mental health at levels similar to the Australian general population norm, and participants attributed these positive results to their increased control over the organisation of their disability support.

7.2.2. Efficient, effective and responsive service delivery

Are personal budgets cost-effective?

The introduction of personal budgets is based on the assumption that they should be at least cost neutral. However the variation in models and service users makes it difficult to compare costs. Small-scale studies in the UK by Jones et al. (2011) and Stainton et al.'s (2009), indicate that personal budget schemes were cheaper than services delivered by the local authority, and relatively cost neutral when compared with independent sector provision. However, both research teams

warn of the need to adequately budget for start-up costs. Stainton et al. (2009) estimated the average cost of establishing a programme site in London was £111,570.

In Australia (Fisher et al., 2010) the average individual annual package funding size was \$28,500 (ranging from \$700 to \$250,000 according to assessed need). The average management cost was 14 per cent of the individual funding package (range 5% to 22%). In the UK the median weekly amount of personal budget ranges from £90 to £213 per week (Hatton and Waters, 2011). In the context of a family based programme (Laragy and Ottmann, 2007) a self-management payment to the value of \$5,000 per annum was provided instead of the provision of traditional case management services. Obviously costs vary considerably in relation to disability support type and support need. Hidden costs are involved in the establishment of personal budget programme such as the provision of support, information and advocacy services, which is discussed in Section 7.

Potential cost savings have been suggested through the stimulation of business processes such as managing access to services, auditing and IT systems, together with reduction in waste, overhead cost reduction and greater value for money (SCIE, 2011). Stainton et al. (2009) conclude that there is some evidence to suggest that direct payments are cheaper than traditional in-house service provision and relatively cost neutral when compared with independent sector provision. The Individual Budgets Evaluation Network (IBSEN) evaluation of the individual budget pilots in 13 local authorities, Glendinning et al. (2008) reported that there appears to be a small cost-effectiveness advantage over standard support arrangements for younger people with a physical disability and people with mental health problems. However, there is virtually no reliable evidence on the long-term social care costs and outcomes of personal budgets in England (SCIE, 2011). In the Australian context, individual funding has not resulted in an increase in the total specialist disability support cost to government (Fisher et al., 2010). In their US study, Dale and Brown (2006) report that the additional costs involved in the provision of personal budgets could be offset by the associated prevention of the need for some nursing home places.

Based on a scan of the relevant research, the Health Foundation concluded that “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” (2010: 3) .

In the Netherlands, the estimated state expenditure on personal budgets in 2007 was considerably less than the budgets for nursing homes or residential care services, and equivalent to home care services (Kremer, 2007). However, van Ginneken et al. (2012) cite the Dutch Ministry of Health reporting that personal

budgets had become unsustainable. “Between 2002 and 2010 the number of personal budget holders increased 10-fold, from 13,000 to 130,000, while spending increased on average by 23% a year from €0.4bn to €2.2bn in the same period, a rate that was much faster than for those without budgets”. A key driver of increased numbers and costs were personal budgets being claimed on behalf of children and adolescents with intellectual disabilities who, previously, had received mainly informal support from their families.

What are the perceptions of frontline staff?

The attitudes of professional service providers who gate keep access to personal budgets was highlighted in many of the reports reviewed. Splander and Vick (2004) discovered early in their pilot research that, in order for it to be successful, local authority senior managers, practitioners and care co-ordinators, had themselves to be willing and able proactively to support direct payment implementation. The reluctance of front-line staff to offer direct payments is evident in several research studies. As early as 2006, Kremer highlighted that training for frontline staff and first-line managers is pivotal to the successful implementation of personal budget schemes. Training is needed to manage change, improve knowledge and assessment practice and promote equality and diversity awareness (Glendinning et al., 2008). It is also needed in order to challenge erroneous perceptions about risk for certain groups (particularly older people, people with mental health problems and/or severe intellectual disabilities) whom professionals might assume are not able to benefit from a personal budget. Tyson (2009) in a study of the introduction of personal budgets in Hartlepool between 2006 and 2009 reported that “there are four areas which must be addressed in the early days: leadership; legitimacy (shared understanding and ownership); a system for resource allocation; and a system for support planning and brokerage” (p. 4). As previously discussed the adoption of the philosophy of personalisation and person centred approaches is critical for the implementation of personal budgets.

What are the implications for personal assistance?

The availability of qualified support workers for disability support and of new types of support services is fundamental for implementing of personal budgets (Timonen et al., 2006). The experience in the Netherlands was that the growth of the care market has been slower than originally anticipated (Kremer, 2006). In the Australian context, particular supply issues for personal budget users living in rural areas have been a challenge (Laragy and Ottmann, 2007). Evidence suggests that personal assistants employed by budget holders regard themselves able to provide a much higher quality of care than is possible when employed by a care organisation, and service users are more satisfied with their support than with traditional personal assistance programmes (Kremer, 2006; Hatton and Waters, 2011). Personal assistants tend to be either known to the service user though

family or social networks. Kremer observes that personal assistants “employed via direct payments sometimes feel obliged, like unpaid family carers, to undertake certain tasks or duties which may be beyond their skills or which may go against their professional standards”, because “clients did not always understand their role as employers” (Kremer, 2006:394). Personal budgets may undermine the professionalism of care in a number of ways: by the employment of family members who would previously have offered care on an informal basis; and through the lack of opportunities for professional development for personal assistants, who cannot consult other professionals or train and educate themselves, and the lack of control over “development of professional knowledge” (Kremer, 2006:395).

One potential problem that can arise from informal care giving is that care givers may feel reluctant to exercise their social rights such as taking the annual leave to which they are entitled. The emergence of an unregulated market of personal assistants may present concerns not only about the quality assurance or care, but also the employment conditions, training and low wages of care providers. Kremer (2006) reported that, in the Netherlands, the state no longer regulates domiciliary care, with half of the caregivers in this study saying they were overburdened as a result of living in the same house with the care receiver.

The Dutch government is increasingly wary of the ‘monetarisation’ of informal care, because, in some cases, people are being paid in circumstances where they would provide care without payment. The debate around payment for previously unpaid, informal carers is complex, and involves ethical, budgetary and social rights issues. The availability of sufficient high quality, trained and skilled personal assistants who are able to offer the type of choice required by personal budget employers, presented challenges in most of the programmes reviewed.

What is the role of support and brokerage services?

In most countries that introduce personal budgets, most people choose support organised through providers or financial facilitators, rather than direct payment (Glasby, 2009; Glendinning 2006). Evidence suggests that many service users need extensive support or brokerage services in order to access personal budget schemes, to manage money, budgeting and accounting, to access the required services, and to employ and manage staff. In the small Australian study by Laragy and Ottmann (2011), families reported that accessing information on personal budgets was time consuming and frustrating, and often professional staff did not themselves understand the funding arrangements and gave contradictory advice. The availability of social and administrative support services is particularly relevant for service users who are vulnerable and/or have impaired decision making capacity. Barriers to up-take for those with degenerative conditions included the need for an appropriate person to manage the direct payment as the

illness progressed (Alzheimer Scotland, 2008). In the Alzheimer Scotland study, many of those interviewed identified the issue of not being able to get a direct payment unless the person with dementia had the capacity to consent, or the family carer had appropriate legal powers in place. The responsibility was seen as daunting and the attitude of staff was cited as an important influence. Some people were not told about direct payments and setting up direct payments was also time-consuming.

Brokerage is an integral part of self-directed support; however, there is some confusion about different types of brokerage and how it differs from advocacy. Access to an independent support broker is provided in the Netherlands, the USA and Canada (Williams, 2008). Complete independence from the agencies which fund, and which have hitherto provided, services has been identified as an essential characteristic of brokerage (Joseph Rowntree Foundation, 1995).

As highlighted in Fisher et al.'s (2010) evaluation of the effectiveness of individual funding, there are potential risks inherent in the provision of poorly managed personal budgets. Effective approaches to personal budgets must therefore include mechanisms to support service users to make informed choices as to the suitability of the personal budgets option and how to administer the budget if they choose to do so. The **In Control** programme in the UK is an example of one such approach, which uses a service user-led organisation to assist people with intellectual disabilities to access and manage personal budgets.

8.0 Implications for Ireland

The commitment to the development of personal budgets in Ireland will involve significant legislative, policy, cultural and service provision challenges. Comparator countries reviewed have experienced difficulties in the provision, administration and uptake of personal budgets programmes. According to Timonen et al. (2006), insufficient dedicated funding for personal budgets, regional differences as to their implementation and a lack of regulation of non-government home care services could all present challenges.

Policy and legislative context

A whole of Government approach and clear departmental leadership is important in the provision of personal budgets. Currently the National Disability Strategy provides a framework for developing and overseeing the necessary changes to culture and structures. Part 2 of the Disability Act, 2005, with its focus on needs assessment followed by an individual service statement, offers a structure to organise supports around the service user, in accordance with person-centred planning. However, the delivery of personal budgets requires changes in how

resources are allocated and how service funding is linked to an assessment of need and person-centred plan. Specific legislation is likely to be required to support a personal budget model (such as the Social Care (Self-Directed Support) (Scotland) Bill currently being considered in Scotland).

In the Netherlands and the UK, personal budgets have been introduced in the broader context of changes in social care and welfare reform. Consideration needs to be given as to what further changes the Irish government needs to make to legislation, policy, and funding, to support the roll-out of new models of personal budgets. While the Government has included the transition to personal budgets in the Programme for Government clear policy, guidance and a definite, detailed plan for implementation has not yet been developed. Currently people with disabilities do not have an automatic right to a personal budget which would enable them to employ a personal assistant (Egan, 2008).

While many other countries deliver personal social services via the local government system, in Ireland overall responsibility for health and personal social services remains with the Department of Health. Development of personal budget policy and the delivery of programmes require the establishment of effective partnerships between the Government and the range of service providers. Voluntary and community service providers may provide useful input into the development of personal budget models, including their design, funding and the building of future capacity.

Funding and providing services

The introduction of personal budget models should not be seen only as a cost saving measure, as this may ultimately deny people with disabilities any real choice. The UK IBSEN's (Glendinning et al., 2008) evaluation report noted that one of the most significant challenges to implementing personal budget schemes was to ensure that each local authority was willing to support creativity and flexibility to allow the service user to determine how each individual budget would be spent. Effectively combining disability funding streams with other sources of funding also proved extremely challenging in the UK.

In remote or sparsely-populated areas, procuring services through competitive tendering may be less effective, and standard pricing may be the best way to ensure value from solo providers. It is critical that any model of tendering is based on value for money - the best price which satisfies core quality criteria. At present Ireland operates neither a competitive tendering model nor an agreed suite of rates for different elements of service. An assessment and planning process producing a monetary allocation (whether real or indicative) is a prerequisite to producing a personalised support system and to building a system which uses resources efficiently and fairly (NDA, 2010).

Evidence suggests (Fisher et al., 2010; Kremer, 2007; Scourfield, 2005) that the growth of a 'care market' can create new challenges particularly in relation to the availability and employment conditions of personal assistants. This can result in problems with recruitment, given competition from other providers, and insufficient applicants with appropriate qualifications/qualities. Scourfield (2005) also points out that the employment of personal assistants by service users with personal budgets has implications for the level of control over the quality of services, together with issues such as adequate funding, availability of professional training, and accountability of personal assistants. Recruitment may be hampered by the low rates of pay if potential employers do not have access to an adequate level of funding.

Currently there are some funding arrangements in Ireland which could provide useful information about how personal budgets should operate and how the transition should be managed. For example, the Home Care Support Scheme (also known as the Home Care Support Package) is a scheme operated by the Health Service Executive (HSE) on an administrative basis. It is generally targeted at older people or those who would otherwise be in hospital or in residential care. While generally it provides for services in kind, in some cases it provides direct cash grants to enable people to purchase a range of services or supports privately. The Home Care Support Scheme is operated at the discretion of the HSE in individual cases, and as yet there are not national guidelines governing eligibility for, or operation of, the scheme.

Existing pilots and new models of personal budgets should continue to be funded and systematically evaluated. Indications from Irish action research conducted by the Brothers of Charity services (2010) are that individualised support packages can result in lower support costs for those with lower support needs, but higher costs for a small number of individuals with high support needs related to severe challenging behaviour. Egan (2008) provides a brief outline of two possible scenarios for the transition to personal budgets in the Irish context. The first option entails capitalising on the potential existing with the Home Care Support Packages currently available through the HSE. As previously discussed, home care packages can in principle provide cash payments however national guidelines and criteria for their delivery and use have yet to be developed. The second option involves developing an extended programme of personal budget projects in partnership with service providers, service users and carers. Section 3 of this paper outlined different models of service delivery offering service users graduated levels of choice and control. Together with these options Egan (2008) recommend the further development of service user organisations for on-going support and advocacy.

Joined-up systems and personal budgets

Moving from traditional service models to a potentially greater range of services sourced from different providers will pose significant challenges for the co-ordination of services at macro and micro levels of service delivery. Personal budgets appear to work best in the context of integrated health and social care, ensuring transparency and improved communication through cross-sector working groups (Spandler and Vick, 2004). There are a number of systems-level issues that need to be resolved within the Irish context, to facilitate the effective implementation of personal budgets, including clarity in the application, eligibility and assessment processes (Coldham et al., 2005; Department of Health (England), 2006). The transition to personal budgets will require close collaboration between health services, social care providers and providers in other sectors such as education, employment, housing and recreation. In particular, key departments and agencies at local level will be important in ensuring that appropriate health and personal supports are identified and provided within the mainstream system, and that systems join up at local level.

Protocols are being developed in a number of areas e.g. on housing and health service supports, to deliver integrated actions. Successful mainstreaming of service provision also requires community services and providers to be equipped to really include people with disabilities. Currently, “not-for-profit disability service providers provide the majority of disability services (90% of intellectual disability services and 60% of physical/sensory disability services), with the remainder largely provided directly by the HSE. Private providers currently play a minimal role” in service provision (NDA, 2010:17). Training and support is therefore needed to enhance the capacity and competence of state agencies, of individual healthcare providers (such as GPs) and of community, cultural and sporting organisations, to enable them to serve individuals with disabilities, including those with complex disabilities (NDA, 2010).

Governance and quality

Another current challenge is to have a standards and inspection regime for disability services (NDA, 2010). The research considered in this review highlights the need to balance safeguarding of service users and the registration of care workers with the desire for individual choice and control. The expansion of personal budgets in Ireland will have workforce implications on the pay and conditions of those contracted by people with disabilities to provide care services. The UK experience demonstrates that, while levels of pay have dropped for personal assistants since the introduction of personal budgets, levels of job satisfaction have increased. There is a need for research to measure the standard of service and level of supervision or training provided by private-care agencies.

Targeted training and support for frontline staff is needed to facilitate the necessary cultural shift in the provision of care and to encourage the take up of personal budgets across groups. In particular, there would be a need to raise awareness and expertise amongst service users, practitioners and other key stakeholders in relation to the use of personal budgets in both child and adult service users (Swift and Hill, 2006; Department of Health (England), 2006).

The Health Act 2007, which established the Health Information and Quality Authority, provides a framework for registering and accrediting service providers, which has not yet been implemented. The function of the Health Information and Quality Authority (HIQA) is to promote the delivery of health and personal social services based on practices that evidence has shown produce high quality, effective and efficient results. It does this by ensuring the services provided in the health system meet nationally agreed standards, both at clinical and managerial level; and assessing whether health and personal social services are managed and delivered to ensure the best possible outcomes within available resources. Given this remit HIQA could be well positioned to undertake a key advisory and monitoring role in the development and delivery of standards in relation to personal budgets. A report on Disability and Mental Health in Ireland: Searching Out Good Practice (Genio, 2009) offers direction on how local examples of best practice can be identified and evaluated.

Brokerage and advocacy services

Experience from the USA suggests that the introduction of personal budgets in Ireland needs to be accompanied by a commitment to support people with disabilities and their families in planning and spending the funds allocated. To do otherwise would be to further disadvantage families by requiring them to assume full responsibility for managing an individual budget – particularly where older people and people with complex needs are concerned. One example which should be noted here is the Cash and Counselling Demonstration (operating across 15 US states) which provides independent professional support to assist in developing a flexible care plan, obtaining services, and managing the budget. The Independent Living Centre in Northern Ireland is another example of the key role of independent brokerage and support services in the delivery of direct payments. The SCIE (2009) research briefing on direct payments also highlights importance of such support.

The Citizens Information Act 2007 provides for the establishment of a Personal Advocacy Service (Citizen Information Board) to assist people with disabilities to access social services. There is a National Advocacy Service in place, however a different scale of operation would be required if it were to take on a brokerage role.

Workforce issues

The implementation of personal budgets depends on the availability of professionals and appropriate community services, such as home-help and personal assistants.

Ireland has existing infrastructure that would facilitate the extended implementation of direct payments. The state has a highly trained workforce and a centralised system of health and social care. Overall, one in four staff members in specialist disability services is a qualified nurse. Ireland's intellectual disability services are significantly nursing-led, reflecting a history of institutional care. Personal assistance services for people with disabilities, predominantly for people with physical disabilities, are currently provided by a number of service provider organisations including the Irish Wheelchair Association, Cheshire Ireland, Enable Ireland, Centres of Independent Living and RehabCare. These are examples of the types of services that could be further developed.

One of the key implications of the extension of personal budgets is the increased use of personal assistants, and potentially decreased use of professionally qualified staff, to provide care and support. A central issue for implementation is therefore the availability, recruitment, training and conditions of employment of personal assistants. This is a resource relatively under developed in the Irish context but is central to the delivery of the quality and flexibility of services that are required (Spandler, 2004; Henwood and Hudson, 2008).

Diversity, life course and personal budgets

Personal budgets may be able to contribute to addressing issues of social justice, citizenship and inclusion for many individuals across the life course, however there is a danger in thinking they are a panacea for structural causes of disablement in Irish society such as poverty, cultural attitudes, institutionalisation or exclusion.

Personal budgets have the potential to play a role in the provision of responsive and creative early intervention and transitional plans for disabled children and young people. The Towards 2016 partnership agreement set out an agreed policy to provide the supports, where necessary, to enable older people to maintain their health and well-being, as well as to live active and full lives, in an independent way, in their own homes and communities for as long as possible, and detailed a series of high-level goals and policy commitments to this end. There is, however, a less well developed policy framework for people with lifelong disabilities as they age. Some disabling conditions are progressive, resulting in significant changes in support needs over time. Regular assessment of needs is important if changing needs are to be captured to inform service provision.

Evidence also suggests that particular sensitivity is required in regard to the provision of personal budgets for people with mental health issues and an awareness of the needs of diverse groups and communities across Ireland (Coldham et al., 2005; Swift and Hill, 2006; Stuart, 2006). Many of the general barriers to personal budgets apply to the mental health field. The split between health and social care funding in the UK is perceived as a major barrier to developing personal budgets in mental health (Glendinning et al., 2008). Given that mental health services are often concerned with the management and control of 'risky behaviour', there are particular concerns about the management of risk for people choosing personal budgets (Spandler and Heslop, 2007).

The difficulties involved in sourcing services and personal assistance in rural areas are also relevant to the Irish context. Consideration may also need to be given to the development of specific outreach strategies to reach others who are less likely to receive personalised services; e.g., people from minority ethnic communities (Newbigging and Lowe, 2005). Support systems for those with mental health problems, and/or intellectual disabilities, could include specialist advocacy and user-led initiatives that provide support. There also needs to be increased awareness and better use of specific tools developed in the mental health field, including joint crisis planning, self-assessment diaries, and guidelines for personal assistance to follow if the personal budget recipient becomes unwell (George, 2002; Luckhurst, 2006; Heslop, 2007).

In conclusion, the proposed transition to personal budgets, in a time of economic recession, presents many challenges and should not be seen as a quick fix. The focus on individually tailored support arrangements should not detract from the necessary investment required for offering a range of options to promote service user control and choice. There will continue to be a need for improving directly managed and provided services for those who still want and/or need them (Spandler and Vick, 2004). Given the historical, economic and cultural context, incremental change may be easier to manage, with both old and new models and services running in parallel during the gradual transition. As well as seeking solutions to individual care issues, it is also essential to continue to address the wider causes of social exclusion.

9.0 Limitations of the existing research

In reading this review, we have endeavoured to bear in mind the following limitations:

- There are limited studies relating to the Irish context

- The quality of the types of studies used to evaluate the impact of personal or personal budgets on people with disability is also limited so the conclusions that can be drawn from the evidence are tentative
- Generalisability to more severe forms of disability is low as the majority of studies excluded more severe populations from the research. For example, people with severe dementia were often excluded, as well as those with less verbal communication ability
- The majority of studies include small sample sizes which may limit the generalisability to the population of people with disabilities
- Reliable evidence on long-term social care costs and implication is not yet available

10.0 Summary

The evidence base for personal budgets, identified by the search strategy in this report, is limited and so it is difficult to draw strong conclusions about the implementation, management and impact of personal budgets although qualitative findings from service users tend to be positive.

Personal budgets could contribute to a radical transformation of social care in Ireland. However the costs and complexities of implementing personal budgets alongside traditional resource allocation systems and service provision present major challenges. This review of experiences in comparator countries identifies the opportunities and limitations that have been encountered with the introduction of personal budgets for people with disabilities.

Consideration of models of personal budgets should be prefaced with an acknowledgement that people with disabilities have individualised and diverse needs and that a 'one model fits all' approach is unlikely to be adequate. Evidence suggests that personal budgets are not appropriate for everyone with disabilities and there is a need for a range of service delivery options responsive to the needs of people with physical, sensory, mental health and/or intellectual disabilities. A positive focus on developing more individually tailored and accessible support arrangements should not detract from necessary investment in improving directly provided services for those who still want and/or need them.

The introduction of personal budgets provides an opportunity to promote people with disabilities' level of choice and control over the support they may need and facilitate their greater inclusion in society which will benefit all (Lyons, 2005; Spandler and Vick, 2004).

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