Synthesis Paper on Personalised Budgets

Introduction

This document synthesis the information provided in a number of key papers[1] relating to personalised budgets both in Ireland and in other jurisdictions, primarily papers previously circulated to Strategy Group. It does this under four main headings drawn from the 2017 Workplan.

- Eligibility and resource allocation
- Supports to apply for an administer personalised budgets
- Governance and accountability
- Financial sustainability

An overall observation is that while plenty of literature was identified on the variety of systems and mechanisms in place to offer personal budgets there is, however, was very little comparative research or evaluation of one approach against another to say what works 'best'.

The document is in two parts:

Part 1: A high-level summary in the form of bullet points on the main findings under each of the Work-plan headings. This is intended to serve as a quick reference to the key points for consideration.

Part 2: A more detailed synthesis of the main research findings, with clear references to the reports used in the compilation of this summary.

[1] For list of research papers included in this synthesis, see References section, page 44

Part 1: Summary findings

1. Eligibility and Resource Allocation

Eligibility

- Eligibility for a personal budget is determined either by the individual applying to the statutory agency for a personal budget or the statutory agency identifying suitable individuals and inviting them for an assessment
- All countries have a citizenship or residency requirement
- About half the countries had an upper age limit of 65
- Most countries have no lower age limit.
- In all countries people with physical, intellectual, developmental and sensory disabilities were eligible
- People with mental illness were eligible in most countries except New Zealand and some provinces in Canada.
- Disabilities have to be long lasting and have a significant impact on the life of the person with the disability
- In some countries a PB can be used to pay for long term residential care
- In some countries a PB can be used to fund early intervention or crisis support

Allowed spending

Table 1: Areas of spend allowed and not allowed in countries with a personal budget system

Allowed by all countries	Not allowed by any country	Allowed by some countries but not by others
• Employment of someone	• Things not related to the disability or that	• Residential care • Respite care

Allowed by all countries	Not allowed by any country	Allowed by some countries but not by others
to provide personal care and support to participate in community activities	will not meet supported person's needs • Day to day living costs • Duplicates of other supports / supports provided by another source within the system • Anything illegal or causing harm or risk to others	• Support for household management e.g. cleaning, cooking • Housing adaptation • Holidays • Day services • Transport • Paying family members

Source: Pike et al, 2016

Evidence on allowed spending

- There are no studies evaluating the benefits of what is permitted spending in one jurisdiction compared to another.
- The review literature recommends flexibility in spending personal budgets as long as it is achieving pre-agreed outcomes
- The literature outlines concerns regarding paying family members but admits that there is very little evidence to support the concerns

Resource allocation

How the system works

- Resource allocation is based on an assessment of need
- The assessment of need is conducted either by a practitioner (who knows the individual) or an independent assessor or sometimes a combination of both or combined with a self-assessment
- There is no clear evidence whether an independent or practitioner led assessment is better although the literature suggests that:

    - a national practitioner led system may be more cost effective.
    - an independent assessment could protect the practitioner relationships with service users.
- Regardless of who does the assessment there is consensus that the assessment should be client-led and outcomes-focussed and provide valid and reliable information on the individual's needs and support systems that are in place
- In general, resource allocation systems are reviewed annually or bi-annually to determine any changes in needs or desired outcomes and whether the budget allocated was appropriate
- The level of transparency of the assessment process and resource allocation systems varies between countries. The link between need and resources often included inaccessible complex algorithms which were not understood by assessors or service users.
- There was little information provided in the literature about an appeals process.

Recommendations from the literature

- Training for staff (funders and assessors) is important to ensure that they are able to implement the resource allocation system consistently but if necessary also challenge service users about the extent of their needs
- The resource allocation system needs to have the financial, administrative and programmatic flexibility to adapt as the supported person's needs change

2. Supports to apply for and administer personalised budgets

Brokerage

- The term 'brokerage' is used in a narrow sense to cover the facilitation of the development of a personal plan (independent of funders or providers) and in its broadest sense to cover a whole range of supports up to and including providing pay roll supports

- There is almost no evidence-base on the effectiveness of brokerage
- In the UK only a small percentage of people used brokerage services for "support for planning personal budgets". Instead personal budget users tend to look for free support brokerage from professionals they already know, rather than pay for professional support brokerage
- The above points not withstanding many service users need extensive support in order to access personal budget schemes, to manage money, budgeting and accounting, to access the required services, and to employ and manage staff"
- The amount and type of support, and who provides it, varies between countries and programmes
- In Fleming's research and his evaluation of the Genio funded personal budget pilot programmes he highlighted a number of supports required by those applying for personalised budgets and other stakeholders[2]
    - easy and transparent access route wish to avail of individualised funding;
    - clear information, particularly around and eligibility and what is expected of personal budget recipients
    - training for support workers / personal assistants particularly around facilitating decision making
    - appropriate training for paid supports and natural supports in order to facilitate a culture of equality - 'Social role valorisation' is one such model in which relevant people could be trained
    - which has been found to increase the status of disabled people, whilst exploring and developing
    - relationships that help these individuals to achieve their desired tasks and outcomes
    - training and real-life opportunities around decision-making for individuals with a disability; this should include considerations about how they

[2] Fleming, P

- Based on the HRB Review and other available reviews, it appears that a package of services is typically provided by the funder or organisations on contract to the funder at no cost to the personalised budget recipient. These supports include:
    - assessment and review of needs
    - person centred planning and review (including risk assessment and safeguarding)
    - guidance on use of personalised budget monies
    - guidance and possibly training on employers' obligations
- Typically, personalised budget recipients can opt to contract with an agency or agencies to:
    - fully manage the budget on behalf of the personalised budget recipient
    - manage the payroll of support workers employed by the personalised budget recipient
    - employ or contract directly all support workers or caregivers who support the personalised budget recipient

Regulating brokerage services

- There is no evidence regarding if and how brokerage services are regulated in other jurisdictions.
- Some reviews have highlighted concerns that the cost of brokerage was reducing people's budget for care and support.
- Many English local authorities provide brokerage (or "support planners")
    - in-house (by separating assessment and planning functions), or
    - by contracting user-led or peer network organisations, or
    - by facilitating informal support of peers and / or families to develop a plan
- An exception to the lack of evidence on the oversight of brokerage is one study which highlighted that in the Netherlands it was found that, "the unchecked proliferation of independent support agencies, and lack of financial oversight, proved problematic when unscrupulous broker

agencies employed aggressive marketing tactics, and in some cases stole parts of the budget".

- One study highlighted concerns in the United Kingdom about conflicts of interest where some organisations are both providing services and brokerage

Organisation of brokerage and other support services

- A review of 11 jurisdiction found that, "the amount and type of support, and who provides it, varies between countries and programmes, but it is frequently referred to as 'brokerage'. It usually involves the provision of information and advice, but may also offer practical help in relation to tasks such as recruiting personal assistants, drawing up contracts of employment, operating a payroll, and so on".
- In the literature reviewed there was very limited discussion of which configuration of support arrangements worked best or was most cost effective.
- A study from Canada found that direct payment[3] and host agency[4] were the most economical, but microboards[5] offered a lot in the form of improved network support and building social capital.
- A review in New Zealand of host agencies suggested that the human resource support/advice and payroll functions carried out by host providers might be provided more efficiently by aggregated host entities operating at national or regional rather than local level.

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[3] "Direct funding" is defined by Stainton et al as a payment which "allows the individual, family or their representative(s) to receive funding directly to retain and manage agreed supports"

[4] "Host agency funding" is defined by Stainton et al as a funding "channelled through an agency selected by the individual or family. The agency then supports the individual and/or their family or representative to utilise and manage their funds for agreed supports"

[5] The microboard, is defined by Stainton et al as "an incorporated entity, [which] is a small (micro) group of committed family and friends (a minimum of five people) who join together with the individual to create a non-profit society to receive and manage the funding. In this structure, the individual requiring support, and their network, are the members of the board, and the board's only purpose is to support the single individual".

3. Governance and accountability

Options for allocation or payment of funding

- There are three main ways that a user can access a personal budget:
  1. a direct payment to their bank account
  2. a payment to an account held by the statutory funding body or a third party who 'manages' it on their behalf, or
  3. a mix of the two
- A distinction between an 'open model' and a 'budgeted or planned model'
  - The 'open model' is where cash payments are allocated with few limited support, few strings attached and limited accounting requirements. In practice, the majority of the cash allowances go to pay informal caregivers in 'open models'.
  - The 'budgeted or planned model', "maintains a more direct connection between a participant's needs and the goods and services purchased to meet those needs". There are more restrictions placed on how the money can be spent (although these vary widely), and they are audited more carefully. The 'budgeted or planned model' is more common. The budgeted or planned model typically consists of the following process

    1. An individual budget is calculated (through a variety of means) for an eligible person, indicating how much is available to spend.

    2. Individuals, usually with a professional (a broker or care planner), identify their needs and desired outcomes through a person-centred planning process. This forms the basis for a spending plan, which must fit within the overall budget allocation.

    3. The spending plan must be approved by the funding agency or a designated agent.

    4. There is often choice as to how the budget is allocated – whether it is given as a direct payment to the individual; passed to a third

party, to which the individual delegates responsibility for commissioning and purchasing the services; or retained by the commissioning organisation (as a 'notional' budget) to spend on the individual's behalf. In some cases, an individual may be able to opt for a combination of these payment methods.

5. Individuals [or the agency managing the budget on their behalf] must then account for any purchases made against their approved spending plan

- The a 'budgeted or planned model' is much more common than 'open model' programmes

Requirements for individuals / families to account for the use of funding

- Table 2 below summarises the financial reporting requirements in each jurisdiction are noted. All the jurisdictions except Austria require financial reporting on expenditure, as summarised in below. The Austrian example was a payment to carers which didn't require a support plan, so perhaps it is not comparable to some of the other schemes.

Table 2 - Personalised Budgets in selected jurisdictions according to financial reporting requirements

Country	Budget deployment	Financial reporting
England	Notional budgets, budgets delegated to third parties, or direct payments.	Detailed financial accounting.
Belgium	Notional budgets (budgets with a drawing right) or direct payments. The choice is not always that of the individual.	Budget holders have to account for all expenditures
France	Direct payment, or paid directly to the service provider.	Use of budgets strictly controlled and users must justify expenditure.
Germany	Direct payment or notional budget.	Accounting always necessary but varies according to locality. Some areas have very strict procedures; others less so.

Country	Budget deployment	Financial reporting
Netherlands	Direct payment with options to outsource some aspects (e.g. salary administration), delegate in full to 3rd party organisation, or to establish a foundation (e.g. pooling budgets to collectively engage assistants)[6].	Budget holders must submit periodic costings of how they spent (all but a tiny percentage of) the money. Costly budget holders are assigned to use a fiscal agent.
Austria	Direct payment. Where individual is cognitively impaired, someone is appointed to manage the budget.	None
US	Cash and counselling pilot used flexible vouchers. Some states provide cash directly, others use fiscal intermediary to handle payments.	Budget holders must account for almost all their expenditure.
Canada	No direct payments. Funds managed by an agency.	Individuals submit 'purchase of service' reports, along with invoices, bi-weekly or monthly.
Australia	No direct payments. Provider always holds the budget.	Limited responsibilities for individuals.
Finland	Service vouchers, given directly to the individual.	No information available.
Sweden	Direct payment, unless beneficiary specifically requests that it be paid to the chosen service provider.	Budget holder sends simple monthly report of the hours of work carried out by the assistants

Education for personalised budget holders around responsibilities as employers

- Typically, either the funder directly or by way of its contract with a host or brokerage service provide some employer supports to personal budget holders who wish to become employers.

[6] This information does not reflect the changes introduced in the Netherlands since 2015.

- Scotland has produced statutory guidance which outlines how local authorities should develop effective arrangements to ensure that all prospective employers are aware of, and discharge, their responsibilities in relation to safe and effective recruitment.
- In New Zealand host agencies provide support and guidance on employers' obligations to personalised budget holders.
- In the USA Cash and Counselling programme, all service users were required to undergo training on how to set up a support plan and how to recruit and train workers.

Quality assurance

- One literature review noted that there is, "no international evidence to suggest that there are any particular risks posed where personal budgets are used to purchase health care. However, this is indicative of the lack of research in this area, rather than a lack of risk".
- A number of reviews have highlighted risks associated with personal budgets rather than any hard evidence of poorer standards of care funded with personalised budgets, these risks include -
    - the expansion of low-quality employment to grow, which has made it very difficult to control the level of quality of both employment and care
    - the creation of in some jurisdictions of unregulated, 'grey' markets which fall outside of employment law
    - 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
- Other research found that personal assistants employed by personalised budget holders who regard themselves able to provide a much higher quality of care than is possible when employed by a care organisation, and that service users are more satisfied with their support than with traditional personal assistance programmes
- One study of English local authorities noted that a number of English local authorities are considering the introduction of a register of personal assistants but notes that such a register would impact on the

trade off between ensuring those providing support have a certain level of skill and support and flexibility for personalised budgets holders to hire whomever they wish to provide them with support

Use of unregulated services

- One review found that, "a number of local authorities engaged in framework agreements with service providers to develop their local market. In most areas these agreements meant that providers were included on a list of approved services, but no level of business was guaranteed with the individual providers. Word of mouth and service user feedback become key factors in supporting providers in the local market"
- An example of how to steer personal budget users towards regulated services is Lincolnshire County Council which has established a **'Service Gateway'**. "In this model, the local authority introduced a set of minimum quality standards to assess providers. Once the providers passed the threshold criteria they were included on a list of approved services in the local area. The list was advertised locally amongst social workers, local charities and other user support groups, as well as service users themselves to ensure users had the information they needed to choose their services"

Adult safeguarding

- Literature highlights the need for personalised budgets arrangement to be aligned with safeguarding considerations.
- Personalised budgets are seen to shift responsibility for care from the service provider to the users themselves which could put service users at risk of abuse and neglect, in particular, if the user purchased unregulated services
- The need for a "cultural shift towards positive risk-taking and risk enablement which should be an integral part of the self-directed support process" is highlighted in some of the literature.
- Despite the point above there is very little discussion about how risks of "abuse or neglect" are managed in the context of personalised budgets.
- Risk, the literature states, can be managed in multiple ways. For example, by:

- firming up adult safeguarding policies
- conducting regular expenditure reviews
- building risk assessment into the support plan
- providing better guidance for care coordinators
- providing better information for personal budget holders
- providing training for staff, users, carers and family members, and;
- conducting regular (appropriate) audits

- One study highlights that it is important that someone (usually the social worker) remains responsible for risk monitoring and risk assessment once the support plan and personal budget are in place

Legal obligations

Where breakdown of support arrangements occurs

- There is little evidence of who is responsible and has a duty of care when personalised budget arrangements breakdown. However, in the UK at least it appears that the local authority [i.e. the funder] does have a duty of care if a direct payment recipient's care / support arrangements breakdown

What recipients agree to

- There is no available overview of what funders and personal budget holders typically agree to

4. Financial Sustainability

The evidence from the literature

- Because personal budget schemes have only recently been introduced or significantly revised in many countries over the last few years there is little evidence with regard to the financial sustainability of these systems.
- The limited number of cost-effective studies of the personalised budget approach versus more traditional approaches found personalised budgets to be cost-effective, although there were come caveats in the findings.

- Cost-effectiveness does not necessarily translate into cost-savings.
- The differing economic models, contexts and systems in each country make comparisons difficult.
- Most schemes have underestimated the costs of implementation, including start-up costs, commissioning, and arranging services, and out-of-pocket expenses. The extent of the underestimation was not available in the documents reviewed
- A very liberal approach to eligibility can lead to increasing expectations and new demand (e.g. The Netherlands).
- People with unmet need in the existing system may drive costs upward in the early years of a personalised budget system[7]
- While short-term savings are unlikely, over time the increased benefit to participants may reap financial rewards of greater employment, better integration with society and, ultimately, less dependency on state supports.
- When budget cuts are necessary it can mean that either eligibility criteria remained the same but the levels of support changed or eligibility criteria are narrowed limiting the number of clients that can avail of the service.
- Of four individualised funding pilots reviewed in Ireland two ceased operation after the e pilot as no mechanism was available to unbundle funding from existing services.

Risks that may affect financial sustainability

- Industrial relations issues relating to staff terms and conditions of employment
    - Some staff fear that the introduction of individualised budgets, where the person chooses their own staff may diminish their role and reduce their responsibilities

[7] Previously unmet need may become apparent because users did not want what was offered before, but through a personal budget can tailor provision appropriately

    - It may be difficult to recruit personal assistants and other, costlier, options may have to be used.
    - A ‘two-tier’ workforce may emerge with unregulated and unprotected personal assistants who are cheaper being hired in place of more expensive regulated and protected workers
- Competition between private suppliers may result in cherry picking leaving the state to provide the uneconomic services
- People may use their individualised budget to pay for things they may have paid for ‘out-of-pocket’ previously.
- Funding may replace family care that is already being delivered free of charge
- Financial risks of double running costs during the transition phase (that is, running the old and new systems in parallel)
- Legal challenges to eligibility criteria (or other aspects of the service) leading to a broadening of criteria (precedent in British Columbia, Canada)
- Fraud of the system through misspending or misrepresentation of the disability
    - the literature suggest that levels of fraud were low and that underspending was more common than overspending or abuse
    - while a high level of regulation can reduce fraud evidence from the literature suggests that levels of regulation did not assisted in reducing fraud
    - high levels of regulation can lead to a substantial administrative burden and lead to people opting out of direct payments.
    - fraud can be reduced during the assessment phase (where service users or service providers can ‘play the system’ to gain more resources) through the development of clear criteria and providing good training to the assessors.
    - fraud can be prevented through the use of online systems of payment which provide a ready audit trail.

- where service users are deemed higher risk then tighter controls can be put around their budget, for example, switching from monthly to weekly payments to limit their scope to over-spend

Recommendations/observations from the literature relating to financial sustainability

- Transitional funding is needed to develop new systems, train staff and fund the piloting and trials of new processes.
- There should be investment in a pilot of a new system to highlight gaps in the system, test funding assumptions and implications, and assist in managing and addressing any challenges that arise.
- Change should be introduced over a fairly long period of time using a strategic and phased approach.
- In some countries the cost of home based care was not be allowed to exceed the cost of long-term residential care.
- A national system is likely to provide economies of scale over disparate local systems.
- Funders of the system need to undertake market development if service users are to be offered real choice. This can lead to efficiencies.
- There needs to be monitoring at a local level to ensure that the prices offered are attractive to providers and still offer choice to users.
- In countries with a decentralized funding and decision making model there was some inequality in access to services
- An individualised funding model is feasible in Ireland but it is crucial to be able to unbundle funding from existing systems to keep the new system budget neutral (excluding set up costs, transitioning costs, etc.).
- New services / brokerage models supporting individualised funding arrangements must negotiate expectation of availability, responsiveness and involvement to avoid overextending resources.
- It may be necessary for a new services/ brokerage models to have an adequate number of people being supported in order for an individualised funding initiative to be financially viable and a geographical focus may be more cost effective

- Seed money is required for new services / brokerage models to get started and they should operate with funds in reserve such that is carries a surplus from year to year to safeguard against unexpected expenses
- A focus on depth and quality rather than scale needs to be at the core of support services.

Part 2: Collation of evidence from current research

1. Eligibility and Resource Allocation

Eligibility

All jurisdictions in the Health Research Board review document (England, Scotland, Canada, Australia, New Zealand and The Netherlands) had a citizenship or residency requirement in order to be eligible for a personal budget (Pike et al, 2016). About half had an upper age limit of 65 but most had no lower age limit. Physical, intellectual, developmental and sensory disabilities that were long lasting and had a significant impact on the life of the person with the disability were common to all jurisdictions. Mental illness was included by most countries except New Zealand and some provinces in Canada. In some countries e.g. the Netherlands, where decisions and responsibility relating to funding are decentralized, local authorities may make decisions relating to eligibility, what is covered, and rates of payment that can lead to unequal access to services. Appendix 1 summarises the main eligibility criteria for personalised budgets these six jurisdictions.

The determination of eligibility varies. In some places the individual applies to the statutory agency for consideration for a personal budget and in other places the statutory agency is responsible for identifying suitable individuals and inviting them for an assessment by themselves or by a contracted organisation.

Permitted spending

While most jurisdictions permitted funding of staff to support home and personal care services and participation in the community there was a lot of variation in other supports that were allowed. For example, some allowed equipment and aids but others did not. Day to day living expenses were excluded by most and some did not permit professional services such as General Practitioners, nurses or physiotherapists particularly if these services were already provided through a nationally subsidised health care

system. In general, if supports were provided by another source within the system they were not allowed to be purchased from the personal budget (Pike et al, 2016). Some countries allowed the funding to be used for residential or respite support. Those that didn't reasoned that there would be less flexibility in how a personal budget could be delivered and less scope to personalise the service in a residential setting. In addition, the personal budget was seen as a tool to retain more people in their own homes, something which people with disabilities desired, with a resulting reduction in costs for authorities (SQW, 2017).

Some countries did not allow funding to be used to pay family members. However, in Scotland and England, in recognition of the importance of the role of the primary carer, the carer is entitled to an assessment of need and may receive funding towards certain supports that help maintain them in their caring role. While SQW (2017) highlights the concerns around paying family members (state paying for services that would otherwise be provided at no-cost and a potentially unhealthy dependent relationship), and recommend that Ireland adopt a policy of non-payment to family members, they concede that there is actually very little evidence to support the concerns. The SQW report concluded that flexibility in spending their personal budgets should be encouraged as long as it is achieving pre-agreed outcomes. Appendix 2 outlines what personalised budgets are allowed and not allowed to fund in each of the jurisdictions.

Resource allocation

The means through which needs are assessed and a personal budget calculated is commonly referred to as a resource allocation system. Case-mix and individualised funding are the most common approaches. More commonly known as 'Personal Budgets', individualised funding is where funding is allocated to each service user based on their individual need generally focused on personal and social care needs.

The assessment of need is conducted either by a practitioner (who knows the individual) or an independent assessor or sometimes a combination of both. Self-assessment is also common in some jurisdictions. There is no clear evidence whether an independent or practitioner led assessment is better although SQW (2017) suggests that a national practitioner led system may be more cost effective. However, they also note that the value

of an independent assessment could help to manage the change anticipated in Ireland and protect the practitioner relationships with service users. Training for staff (funders and assessors) is important to ensure that they are able to implement the resource allocation system consistently but if necessary also challenge service users about the extent of their needs (SQW, 2017)

Once accepted, a plan is developed with the individual either directly with the statutory agency or through an intermediary agency. In England, the amount of money derived through the resource allocation system is widely described as an indicative budget, which provides a basis for planning. In most cases the assumption is that the indicative budget will become the actual budget, but there are cases where additional amounts have been made available to meet recognised needs. (SQW, 2017). Funds can be disbursed either directly or through the intermediary. In general, resource allocation systems were reviewed annually or bi-annually to review whether or not the persons' needs or desired outcomes have changed, and whether or not the budget allocated was appropriate and sufficient to enable them to meet the agreed outcomes. Changes could be made accordingly and mechanisms need to be in place to trigger a review if necessary before the official review time. This may be necessary where life circumstances result in changed needs and the system needs to have the financial, administrative and programmatic flexibility to adapt to meet the new set of needs.

Regardless of who does the assessment there is consensus that the assessment should be client-led and outcomes-focussed (Wilberforce et al, 2014), and provide valid and reliable information on the individual's needs and support systems that are in place (SQW, 2017). In general, the level of transparency of the assessment process and resource allocation systems that was in use varied between countries. In most countries the assessment process was clearer. However, the link to resources often included inaccessible complex algorithms which were not understood by assessors let alone service users. The general understanding was that the more needs that the assessment identified the more resources would be allocated. People with disabilities would compare their allocation with others they knew with a disability (SQW, 2017).

There was little information provided in the documents synthesised about an appeals process. SQW recommended a moderation panel to ensure consistency across different assessors and an equitable system.

2. Supports to apply for and administer personalised budgets

Brokerage

The evaluation of Possibilities Plus notes that the term brokerage has "definitional difficulties" (Kendrick Consulting, 2016). In the literature the term brokerage appears to be used in a narrow sense to cover facilitation of the development of a personal plan (independent of funders or providers) and in its broadest sense to cover a whole range of supports up to and including providing pay roll supports.

Gladsby (2013), citing a research review in the UK noted that there is virtually no evidence-base in the UK relating to the practice of support brokerage as it has developed. The effectiveness of brokerage is also, Gladsby noted, little discussed in programmes in other countries.

Gadsby (2013) reported that in the Netherlands, "the unchecked proliferation of independent support agencies, and lack of financial oversight, proved problematic when unscrupulous broker agencies employed aggressive marketing tactics, and in some cases stole parts of the budget".

The SQW report stated that in the UK, users tended to look for free support brokerage from professionals they already know, rather than pay for professional support brokerage, (SQW, 2017).

The SQW report found that, "**there is little evidence on the impact of brokerages"** and that if "independent assessors are used there may be less need for service user support, at the assessment stage, as the assessor could use their independence to also offer such support" (SQW, 2017).

The 3rd POET (Personal Budget Survey) report in the United Kingdom asked personal budget recipients about, "support for planning personal budgets". About half of respondents said that the received support with planning

from the Council [i.e. the funder], over a third from family and friends and less than 10% from brokers (Waters and Hatton, 2014).

The 3rd POET (Personal Budget Survey) report provides details of who managed the budget of personal budget recipients

- direct payments paid to the individual (33.4%)
- direct payments looked after by a friend or family member (20.5%)
- personal budget managed by a provider (19.7%)
- council or NHS-managed personal budgets (18.3%)
- personal budgets managed by a broker (5%)

Gladsby in her review of 11 jurisdictions states that the, "the amount and type of support, and who provides it, varies between countries and programmes, but it is frequently referred to as 'brokerage'. It usually involves the provision of information and advice, but may also offer practical help in relation to tasks such as recruiting personal assistants, drawing up contracts of employment, operating a payroll, and so on".

Carter Anand et al found 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" Carter Anand et al.

The 3rd POET (Personal Budget Survey) highlighted difficulties personal budget holders experienced in relation to aspects of the process. Difficulties were experienced in relation to:

- making changes to support (28.4%);
- information and advice (24.1%); and
- understanding restrictions placed on the use of the personal budget (23.6%)
- agreeing the budget (22.9%)
- getting support (21.2%),
- choosing support (19.5%)
- planning support (19.5%)

The HRB review (Pike et al, 2016) shows that a number of jurisdictions offer a personalised budget holders the option of

- Self / family
- Host agency managed

And also possibly

- Funder managed

An example cited in the HRB Review was that of Community Living British Columbia Individualised Funding programme, which allows individuals and families to arrange and manage the supports and services they require to meet disability-related needs or to select an agency to employ or contract directly with all support workers or caregivers. The Host Agency are then responsible for ensuring that the supports and services purchased with these funds comply with relevant policies and programme standards (Pike et al, 2016).

In New Zealand those approved for a Personalised Budget (called Enhanced Individualised Funding) are referred to a host agency (an agency on contract to provide supports to personalised budget recipients). The host agency must provide certain supports. These supports are

- supporting the person with advice on the management of support staff and budgets;
- receiving information from the person that verifies the delivery of the support services (such as timesheets or expense claims);
- making sure that the person is fully informed about their entitlements (and any limitation on those entitlements);
- ensuring that all expenditure is within the Purchasing Guidelines;
- assisting and coaching the person in managing their funding budget, and ensuring that expenditure is within funding limits and that no over expenditure of allocated budget is incurred;
- reviewing at regular intervals how the person is managing with the support arrangements to ensure that the provision of the services meets the needs of the person, and
- ensuring that appropriate administrative processes are complied with and appropriate records are kept.

The personalised budget recipient can choose to receive support beyond the basic package of supports **at a cost**. These supports include:

- monthly statements

- payroll services
- completion of tax requirements (i.e. PAYE, Accident Compensation Corporation employer levies and KiwiSaver [pension] contributions)
- membership of the Employers' Association
- additional budgeting tools
- help with recruitment

It appears therefore, based on the HRB Review and other available reviews, that a package of services is typically provided by the funder or organisations on contract to the funder at no cost to the personalised budget recipient. These supports include:

- assessment and review of needs
- person centred planning and review (including risk assessment and safeguarding)
- guidance on use of personalised budget monies
- guidance and possibly training on employers' obligations

Typically, personalised budget recipients can opt to contract with an agency or agencies to:

- fully manage the budget on behalf of the personalised budget recipient
- manage the payroll of support workers employed by the personalised budget recipient
- employ or contract directly all support workers or caregivers who support the personalised budget recipient

Different support arrangement for personal budget recipients operate in different jurisdictions and in some cases within jurisdictions. In the literature reviewed there was very limited discussion of which configuration of support arrangements worked best or was most cost effective.

The HRB Report, citing Stainton and colleagues (Stainton et al. 2013,) reported that direct payment[8] and host agency[9] were the most economical,

[8] "Direct funding" is defined by Stainton et al as a payment which "allows the individual, family or their representative(s) to receive funding directly to retain and manage agreed supports"

but microboards[10] offered a lot in the form of improved network support and building social capital. The HRB report, cites a study by Stainton et al. 2013, who found that although personalised budgets, "bestowed many benefits, such as greater independence, choice and flexibility, the administrative burden can be very onerous for individuals and families" (Pike et al, 2016).

A review in New Zealand of host agencies suggested that the human resource support/advice and payroll functions carried out by host providers might be provided more efficiently by aggregated host entities operating at national or regional rather than local level.

In Fleming's research and his evaluation of the Genio funded personal budget pilot programmes he highlighted a number of supports required by those applying for personalised budgets and other stakeholders[11]

- easy and transparent access route wish to avail of individualised funding;
- clear information, particularly around and eligibility and what is expected of personal budget recipients
- training for support workers / personal assistants particularly around facilitating decision making
- appropriate training for paid supports and natural supports in order to facilitate a culture of equality - 'Social role valorisation' is one such model in which relevant people could be trained

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[9] "Host agency funding" is defined by Stainton et al as a funding "channelled through an agency selected by the individual or family. The agency then supports the individual and/or their family or representative to utilise and manage their funds for agreed supports"

[10] The microboard, is defined by Stainton et al as "an incorporated entity, [which] is a small (micro) group of committed family and friends (a minimum of five people) who join together with the individual to create a non-profit society to receive and manage the funding. In this structure, the individual requiring support, and their network, are the members of the board, and the board's only purpose is to support the single individual".

[11] Fleming, P

- which has been found to increase the status of disabled people, whilst exploring and developing
- relationships that help these individuals to achieve their desired tasks and outcomes
- training and real-life opportunities around decision-making for individuals with a disability; this should include considerations about how they

3. Governance and accountability

Options for allocation or payment of funding

There are three main ways that a user can access a personal budget:

5. a direct payment to their bank account
6. a payment to an account held by the statutory funding body or a third party who 'manages' it on their behalf, or
7. a mix of the two

Vouchers and pre-paid cards have been used in direct payments, which allowed users to avoid setting up a bank account for their direct payments and allowed them to easily pay for services although, this has been less common.

A number of jurisdictions have different combinations of these options available to personalised budget recipients. The reforms in the Netherlands since 2015 have meant monies are no longer paid into the bank accounts of individuals but individuals can nonetheless make decisions on supports to be purchased by a third party.

Gadsby, citing (Alakeson 2010) draws a distinction between an 'open model' and a 'budgeted or planned model model'. The 'open model' is where cash payments are allocated with few limited support, few strings attached and limited accounting requirements. In practice, the majority of the cash allowances go, Gadsby notes, to pay informal caregivers in 'open models'.

The ‘budgeted or planned model’, “maintains a more direct connection between a participant’s needs and the goods and services purchased to meet those needs” (Gladsby, 2013). There are more restrictions placed on how the money can be spent (although these vary widely), and they are audited more carefully. The ‘budgeted or planned model’ is more common according to Gladsby. The budgeted or planned model typically consists of the following process

1. An individual budget is calculated (through a variety of means) for an eligible person, indicating how much is available to spend.

2. Individuals, usually with a professional (a broker or care planner), identify their needs and desired outcomes through a person-centred planning process. This forms the basis for a spending plan, which must fit within the overall budget allocation.

3. The spending plan must be approved by the funding agency or a designated agent.

4. There is often choice as to how the budget is allocated – whether it is given as a direct payment to the individual; passed to a third party, to which the individual delegates responsibility for commissioning and purchasing the services; or retained by the commissioning organisation (as a ‘notional’ budget) to spend on the individual’s behalf. In some cases, an individual may be able to opt for a combination of these payment methods.

5. Individuals [or the agency managing the budget on their behalf] must then account for any purchases made against their approved spending plan.

Of the 10 jurisdictions for which Gladsby obtained relevant information, 9 made the provision of a personal budget dependent on having an agreed “personalised care plan” (Gladsby, 2013).

Requirements for individuals / families to account for the use of funding

In Gladsby’s review of 11 jurisdictions, cited in the HRB Review, the financial reporting requirements in each jurisdiction are noted. All the

jurisdictions except Austria require financial reporting on expenditure, as summarised in Table 1 below. The Austrian example was a payment to carers which didn't require a support plan, so perhaps it is not comparable to some of the other schemes.

The Saskatchewan Home Care Program, which is an example of a programme where a direct payment is payed to an individual to employ their own staff. The requirement of this scheme appear to be relatively basic. The scheme requires recipients to;

- have a separate back account,
- submit staff time sheets monthly, and
- submit a quarterly financial report, which includes monthly bank statements.

Where monies are paid directly to a broker or other intermediary it is in many cases the intermediary that is required to meet the reporting requirements. Therefore, it may be that there will be different reporting requirements for families / individuals depending on the type of personalised budget arrangement that they choose.

Table 1 - Personalised Budgets in selected jurisdictions according to financial reporting requirements

Country	Dependent on a personalised care plan?	Budget deployment	Use	Financial reporting
England	Yes	Notional budgets, budgets delegated to third parties, or direct payments.	IBs usually used to purchase mainstream services, employ personal assistants (PAs) and pay for leisure activities; sometimes used for wide range of one-off purchases. PHBs used to employ PAs or purchase goods or services that contribute to health goals in personal plan. Not to pay for GP services or emergency health services.	Detailed financial accounting.
Belgium	Yes (set of assessment tools)	Notional budgets (budgets with a drawing right) or direct payments. The choice is not always that of the individual.	PAB can be used to employ a PA. PGB can be used to employ PAs and purchase services from choice of providers. At least 95% of the budget must be used for the payment of salaries.	Budget holders have to account for all expenditures
France	Yes (defined by professionals)	Direct payment, or paid directly to the service provider.	Used to fund specific care packages, and/or to employ a PA.	Use of budgets strictly controlled and users must justify expenditure.
Germany	Yes	Direct payment or notional budget.	To purchase transport, nursing, assistance at workplace, leisure activities, therapy costs, support equipment, etc, and services provided by health insurance/care insurance,	Accounting always necessary but varies according to locality. Some areas have very strict procedures; others

Country	Dependent on a personalised care plan?	Budget deployment	Use	Financial reporting
			when needed regularly and on a supplementary basis. GP costs cannot be paid for.	less so.
Netherlands	Yes (introduced 2012)	Direct payment with options to outsource some aspects (e.g. salary administration), delegate in full to 3rd party organisation, or to establish a foundation (e.g. pooling budgets to collectively engage assistants)[12].	To buy personal care for help with daily living; nursing care; support services (e.g. day-time activities), and short stay and respite care for short holidays/weekends. Not allowed for alternative treatments, medical treatments, or treatment by allied health professionals.	Budget holders must submit periodic costings of how they spent (all but a tiny percentage of) the money. Costly budget holders are assigned to use a fiscal agent.
Austria	No	Direct payment. Where individual is cognitively impaired, someone is appointed to manage the budget.	Largely used to compensate family members for informal care.	None
US	Yes	Cash and counselling pilot used flexible vouchers. Some states provide cash directly, others use fiscal intermediary to handle payments.	Varies between programmes. Can employ PAs and purchase care-related services and goods. States control the range of services and equipment that can be purchased. Some programmes include purchasing of some elements	Budget holders must account for almost all their expenditure.

[12] This information does not reflect the changes introduced in the Netherlands since 2015.

Country	Dependent on a personalised care plan?	Budget deployment	Use	Financial reporting
			of health care such as skilled nursing and long-term rehabilitative therapies. Some include clinical recovery services for people with serious mental health conditions.	
Canada	Yes	No direct payments. Funds managed by an agency.	To purchase disability-related supports. Not for costs related to medical supplies or equipment, home renovations, electronic equipment or leisure, recreation & personal/family costs.	Individuals submit 'purchase of service' reports, along with invoices, bi-weekly or monthly.
Australia	Yes	No direct payments. Provider always holds the budget.	CDC programme: includes purchasing of personal assistance, nutrition, home help, transport and emotional support.	Limited responsibilities for individuals.
Finland	Yes	Service vouchers, given directly to the individual.	Purchasing of care (and, post 2009, health) services from specified providers.	No information available.
Sweden	-	Direct payment, unless beneficiary specifically requests that it be paid to the chosen service provider.	No restrictions, except it cannot cover medical treatment. Generally used to employ PAs	Budget holder sends simple monthly report of the hours of work carried out by the assistants

Education for personalised budget holders around responsibilities as employers

From the HRB report it appears that typically either the funder directly or by way of its contract with a host or brokerage service provide some employer supports to personal budget holders who wish to become employers.

Scotland has produced statutory guidance which outlines how local authorities should develop effective arrangements to ensure that all prospective employers are aware of, and discharge, their responsibilities in relation to safe and effective recruitment.

In New Zealand and the Netherlands host or brokerage type services provide support and guidance on employers' obligations to personalised budget holders.

In the USA Cash and Counselling programme, all service users were required to undergo training on how to set up a support plan and how to recruit and train workers.

In England local authorities typically contract an agency to provide direct payment recruitment and retention support service enable people who are employing their own personal assistant to live independently in their own homes, to achieve their goals in life and to help them play an active part in their community.

Specific support relating to employing a Personal Assistant from one sample Local Authority[13] [funder] includes the following:

- An introduction to becoming an employer including an "Employers Toolkit"
    - Support to recruit a personal assistant including
    - Creating and placing an advert
    - Creating a job description and person specification

[13] Warwickshire County Council, (?) The Recruitment, Retention and Employment Support Service

    - Providing, sending out and receiving application forms
    - Supporting with shortlisting candidates
    - Sourcing interview venues
    - Sending out letters to invite to interviews or decline
    - Supporting with interview questions and at the interviews if required Sending out correspondence to successful and unsuccessful candidates
    - Support with getting references/DBS checks and checks to ensure the candidate is legal to work in the UK
- Contracts of employment
- Information on paying the minimum national wage
- Paying tax and NI
- Abiding by the working time directive
- Workplace pensions
- Guidance on a payroll service
- They will make a referral to the payroll support organisation who will generate a 4 weekly payslip
- Advice on understanding the role and responsibilities of an employer

As mentioned above, in most jurisdictions employers' supports beyond training and guidance (HR and payroll) are available through an agency or agencies at a cost to personal budget holders.

Quality assurance

Gladsby review of evidence states that there is, "no international evidence to suggest that there are any particular risks posed where personal budgets are used to purchase health care. However, this is indicative of the lack of research in this area, rather than a lack of risk" (Gladsby 2013).

A number of reviews have highlighted risks associated with personal budgets rather than any hard evidence of poorer standards of care funded with personalised budgets, these risks include -

- the expansion of low-quality employment to grow, which has made it very difficult to control the level of quality of both employment and care (Gladsby 2013).
- the creation of in some jurisdictions of unregulated, 'grey' markets which fall outside of employment law (SQW, 2017).
- 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 (Carter Anand et al, 2012).

Carter Anand et al highlighted studies of personal assistants employed by personalised budget holders who 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 (Carter Anand et al 2012).

Needham and Duffy noted that a number of English local authorities are considering the introduction of a register of personal assistants but notes that such a register would impact on the trade off between ensuring those providing support have a certain level of skill and support and flexibility for personalised budgets holders to hire whomever they wish to provide them with support (Needham and Duffy, 2012).

Use of unregulated services

In traditional social care models the role of the funder was to identify suitable service providers and fund or commission the services of those providers for the eligible population. However, in a personalised budget model the focus of the funder will need to shift, "to developing a local market from which service users could purchase services independently" (SQW, 2017).

The SQW report describes how this new role for funders operates: "a number of local authorities engaged in framework agreements with service providers to develop their local market. In most areas these agreements meant that providers were included on a list of approved services, but no level of business was guaranteed with the individual providers. Word of mouth and service user feedback become key factors in supporting providers in the local market. Local authorities often set out quality

standards and criteria that providers had to demonstrate they could meet before they were included in the local market offer. Quality was then monitored through users' feedback"

The SQW report provides a practical example of how this model is operated by Lincolnshire County Council. Lincolnshire County Council have established a **'Service Gateway'**. "In this model, the local authority introduced a set of minimum quality standards to assess providers. Once the providers passed the threshold criteria they were included on a list of approved services in the local area. The list was advertised locally amongst social workers, local charities and other user support groups, as well as service users themselves to ensure users had the information they needed to choose their services" (SQW, 2017).

The sample agreement between an English Local Authority and Personal Budget Recipients "strongly recommend" but does not require direct payment recipients who use agencies to, "check and only use social care providers or agencies that are registered with the Care Quality Commission [i.e. the Statutory Regulator] to provide services to you."[14]

Oversight of brokerage services

There does not appear to be published evidence regarding if and how brokerage services are regulated in other jurisdictions. Needham and Duffy suggest that there is little support for the, "new profession of independent broker" in the United Kingdom. Key informants to the SQW report (2017) highlighted cost and concerns that the cost of brokerage was reducing people's budget for care and support.

Needham and Duffy state that most English local authorities provide brokerage (or "support planners")

- in-house (by separating assessment and planning functions), or
- by contracting user-led or peer network organisations, or
- by facilitating informal support of peers and / or families to develop a plan (Needham and Duffy, 2012)

[14] Warwickshire County Council (2014) Direct Payment Agreement

The SQW reported found that there is some level of reluctance to introduce brokerage services in Scotland, as many saw this as taking responsibilities away from the social workers who managed the case (SQW, 2017).

Needham and Duffy also highlights that there are concerns in the United Kingdom about conflicts of interest where some organisations are both providing services and brokerage.

Adult safeguarding

The SQW report states that, "across the literature, and amongst the various stakeholders with whom we consulted there was an acknowledgment that personalisation needed to be aligned with safeguarding considerations. The person centred approach empowered service users by increasing the level of choice and control that they had over the shape of the support package that they received. However, this approach could be perceived as 'risky' for service users. The shift of responsibility over their care from the service provider to the users themselves could put them at risk of abuse and neglect, in particular, if the user purchased unregulated services. In addition, there was risk of a lack of support, for individuals who did not have a family or other informal support networks" (SQW, 2017)

Gladsby, in her study of 11 jurisdictions, noted that- "the review process in international programmes is rarely discussed. Within the US Cash and Counselling programme, it is noted that the 'counselling' element incorporates regular checks on the budget holder for evidence of abuse or neglect (which were rarely observed)".

The SQW Report goes on say that, "adult safeguarding is not the same as child protection (adults need advice and support but the freedom to make their own decisions) but statutory services have a duty to ensure that vulnerable adults are appropriately protected from harm or abuse. People's safeguarding needs vary and there is a need to avoid a 'one-size-fits-all' approach to regulation (Glasby, 2011). It is very hard to manage risk without proper context. **Person-centred planning leading to the care package was perceived to be the key"** (SQW, 2017).

The SQW Report, identified the necessity of a "cultural shift towards positive risk-taking and risk enablement which should be an integral part of the self-directed support process".

Risk, the SQW report states, can be managed in multiple ways. For example, by:

- firming up adult safeguarding policies
- conducting regular expenditure reviews
- building risk assessment into the support plan
- providing better guidance for care coordinators
- providing better information for personal budget holders
- providing training for staff, users, carers and family members, and;
- conducting regular (appropriate) audits

The SQW Report, concludes that, "it is important that someone (usually the social worker) remains responsible for risk monitoring and risk assessment once the support plan and personal budget are in place" (SQW, 2017).

The sample agreement between an English Local Authority and Personal Budget Recipients[15] recommends but does not require that direct payment recipients carry out checks with the Disclosure and Barring Service [vetting] on any staff they are intending to employ. However, if there will be children present in the household where the Personal Assistant will be working and children will be work then Council [i.e. the funder] **must** undertake the checks on that direct payment recipient's behalf.

Legal obligations

Where breakdown of support arrangements occurs

The sample direct payments agreement from England between the local authority / funders and direct payment recipients required the recipients to have a contingency plan for when care arrangements break down. However, the agreement also state that the local authority [i.e. the funder]

[15] Warwickshire County Council (2014) Direct Payment Agreement

does have a duty of care if a direct payment recipient's care / support arrangements breakdown[16].

Direct payment recipients are required in their agreement with the funder to notify them of any breakdown in service.

What recipients agree to

There is no detailed overview of what funders and personal budget holders typically agree to. An example of one personalised budget (direct payment) funder – recipient agreement from England[17] required recipients to agree to

- setting up a separate bank account and providing the funder with the full and correct details of this account.
- paying an appropriate contribution into the account by standing order or direct debit every four weeks (social care in the United Kingdom is means tested)
- using the Direct Payment (including the person's own Contribution) only for equipment or a service which enables the recipient to achieve their agreed outcomes and meet the needs as agreed in the recipient's Plan
- not spending personal budget monies on a specified range of categories of services and items
- complying with all the legal requirements which arise from any arrangements made in using the Direct Payment
- getting the funders written agreement prior to using the Direct Payment to pay for services from a spouse, civil partner, relative or other person who lives in the same household
- keeping clear records of the Direct Payment money the recipient has received and how it is being used to meet the recipient's needs and agreed outcomes
- planning and making contingency arrangements in case the support you need breaks down

[16] Warwickshire County Council (2014) Direct Payment Agreement

[17] Warwickshire County Council (2014) Direct Payment Agreement

- paying back to us any Direct Payment money which is not used to meet the recipient's agreed outcomes as set out in the recipient's Plan
- returning this to the funder any unspent monies in the recipient's Direct Payment Account above an agreed threshold
- share personal information in order to help to ensure that the recipient's needs are met appropriately

4. Financial Sustainability

The introduction of personal budgets is still a 'work in progress' with personal budget schemes only recently introduced or significantly revised in the last few years in many countries. Therefore, there is a dearth of evidence regarding the financial sustainability of personal budgets (Pike et al, 2016, SQW, 2017). The differing economic models, contexts and systems in each country make comparisons difficult. This is compounded by the fact that in some countries different local areas administer the budgets in different ways and some countries draw a clear distinction between health and social care services and others do not. Pike et al (2016) found that transaction costs (implementation, commissioning and arranging services) are almost never fully accounted for in health care cost estimations. Open ended budgets are difficult to justify and some countries impose caps that can only be changed through legislation (e.g. Germany). Experience from the Netherlands shows that a very liberal approach to eligibility led to increasing expectations and new demand. An assessment of long-term financial sustainability requires forecasting. In Australia a 25-year projection as a percentage of gross domestic product factoring in the ageing population was conducted to examine sustainability. After its first year of implementation the new Australian system was deemed sustainable (Pike et al, 2016).

The limited number of cost-effective studies of the personalised budget approach versus more traditional approaches found personalised budgets to be cost-effective, although there were come caveats in the findings (Pike et al 2016). However, cost-effectiveness does not necessarily translate into cost-savings and some countries found that costs were higher than expected at the beginning of the personalised budget scheme and

increased the following year. This was explained largely by people with unmet need in the existing system and it was considered that costs would eventually even out. They also found that outcomes were greater and therefore felt that the money was well spent. While short-term savings are unlikely over time the increased benefit to participants may reap financial rewards of greater employment, better integration with society and, ultimately, less dependency on state supports (Pike et al, 2016).

Industrial relations issues and the supply of staff could affect financial sustainability. The perception of some staff, may be that the introduction of individualised budgets where the person chooses their own staff may diminish their role and reduce their responsibilities (SQW, 2017). Other issues may arise where it is difficult to recruit personal assistants and other, costlier, options have to be used. There is also the danger of a 'two-tier' workforce emerging with unregulated and unprotected personal assistants who are cheaper being hired in place of regulated and protected workers who are more expensive (Pike et al, 2016). Pike et al also identified other risk such as where competition between private suppliers may result in cherry picking and which could leave the state to provide the uneconomic services and where some people may use their individualised budget to pay for things they may have paid for 'out-of-pocket' previously.

Transitioning

The SQW review (2017) and Pike et al (2016) found very limited evidence in the literature with regards to the cost of transitioning to an individualised funding system. Some findings of note were that:

- most schemes in the EU have underestimated the costs of implementation, including start-up costs, unpaid care provided by families and out-of-pocket expenses (however, the extent of the underestimation was not available in the documents reviewed
- there are financial risks of double running costs (that is, running the old and new systems in parallel)
- previously unmet need may become apparent (often because users did not want what was offered before, but through a personal budget can tailor provision appropriately)

- transitional funding is needed to develop new systems, train staff and fund the piloting and trials of new processes and
- change should be introduced over a fairly long period of time.

The SQW consultations highlighted the benefits of investing in a pilot of a new system, as part of the transition process which could highlight any gaps in the system, test funding assumptions and implications, and assist in managing and addressing any challenges that may arise during the pilot. Sufficient time should be given to draw out the lessons learned to be fully understood and before full implementation.

Managing costs

When budget cuts are necessary it can mean that eligibility criteria remained the same but the levels of support given or the range of needs supported change. In general, those with less severe needs were more likely to receive a reduction) (SQW, 2017). Where eligibility criteria are narrowed it limits the number of clients that can avail of the service and potentially the range of services available. In the Netherlands this led to unmet needs and waiting lists. There is precedent for legal challenges to eligibility criteria leading to a broadening of criteria in, for example, British Columbia, Canada (Pike et al, 2016). In some countries the cost of home based care would not be allowed to exceed the cost of long-term residential care. Managing expectation and payments for family inputs is clearly important for budget control. If care is not taken the state could end up facing a large bill for family care that is already being delivered free of charge (SQW 2017). The SQW paper also recognised that a national system is likely to provide economies of scale over disparate local systems. Pike et al, (2016) emphasise that it is critical to have the infrastructure in place and to use a strategic and phased approach to the introduction of an individualised budget scheme

In developing choice there can be conflicts with price, as economies of scale can be lost. There needs to be monitoring at a local level to ensure that the prices offered are attractive to providers and still offer choice to users (SQW 2017). Funders of the system need to undertake market development if service users are to be offered real choice. This can lead to efficiencies as more providers enter the market and some existing providers may be exposed if they are offering services at a higher price or

inefficiently. In some cases, political decisions can be taken to protect some provision.

Fraud

A key part of financial sustainability is to minimise fraud. One way to do this is to have a high level of regulation. However, the literature did not provide any evidence to suggest that high levels of regulation assisted in reducing fraud (SQW, 2017). England, which has a high level of regulation, found that there was a resulting substantial administrative burden on service users and social workers and reportedly led to people opting out of direct payments. Evidence from England, and anecdotally from Scotland, would suggest that the levels of abuse of the system by those with direct payments was low. Underspend was reported as being more common than overspending or abuse. This was thought to be either due to an initial over allocation or due to service users being cautious with their allocation in case something went wrong. Fraud can be prevented through the use of online systems of payment which provide a ready audit trail. Where service users are deemed higher risk then tighter controls can be put around their budget, for example, switching from monthly to weekly payments to limit their scope to over-spend. (SQW 2016)

Fraud can also occur during the assessment phase where service users or service providers 'play the system' to gain more resources. SQW (2017) recommended that clear criteria are developed and that good training is provided to the assessors.

Lessons from Ireland

Fleming (2016a) evaluated the implementation of four pilot individualised funding initiatives for people with disability in Ireland. The models used in each of the pilots varied with examples of direct payment, direct payment using a broker, independent support broker and a self-management model. Of the four, two ceased operation after the end of the pilot as no mechanism was available to unbundle existing HSE funding from existing services. The other two services remain in operation with HSE funding on a person by person basis. It would seem therefore the ability to unbundle funding is crucial to being able to introduce a personalise budget system that is budget neutral (excluding set up costs, transitioning costs, etc.).

overall the evaluation concluded that an individualised funding model was considered feasible in Ireland (Fleming et al, 2016b)

Kendrick (2016), who evaluated one of the pilots in depth, noted that setting up models of practice that are new and untested risk over commitment and over extension. It is necessary to have a means available to negotiate expectation of availability, responsiveness and involvement to avoid overextending existing resources. He also noted that it may be necessary for an agency to have an adequate number of people being supported in order for an individualised funding initiative to be financially viable and that seed money is required to get started. However, despite the need for financial stability, a focus on depth and quality rather than scale needs to be at the core of support services. An important point he raises is that properly supporting someone to lead the life they want to lead is labour intensive and that if not adequately resourced

> 'the balance will shift from personal growth and development to minimalistic custodial care' (Kendrick, 2016, p34)

He also recommended that the agency should operate with funds in reserve such that is carries a surplus from year to year to safeguard against unexpected expenses. It would seem that this advice would be relevant to all agencies that managed personalised budget arrangement. Other activities that may make an agency more efficient would be to have a geographical focus as there are more challenges, including increased expenses, in serving people who are geographically more remote when compared to those who live in close proximity to the agency.

Table 1: Eligibility Criteria

Criteria	Scotland	England	Australia	New Zealand	Canada*	Netherlands

Citizenship/residency requirement	YES	YES	YES	YES	YES	YES
Age						
Min age	NO	18 y	NO**	NO	16-19y (no age restrictions mentioned in SK)	No
Max age	Uses discretion	Not specified	<65	65***	65 (no age restrictions mentioned in SK)	Not specified
Living in long term residential care	Eligibility ends	PB may be used to pay for residential care	Eligibility ends	Yes can receive	Yes (NB)	Unclear
Nature of disability	Infirmity, illness, mental disorder or disability – all ages	Physical or mental impairment or illness. Unable to achieve at least two outcomes on a list of 11 specified outcomes.	Includes intellectual, cognitive, neurological, sensory, physical and psychiatric	Physical, intellectual or sensory. Also some developmental such as autism and some neurological conditions. Excludes mental illness, chronic illness and conditions associated with ageing	Separate schemes for different categories of disability e.g. physical = home care programmes which are generally self-managed developmental = disability support programme. Mental health included in some provinces e.g. MB and excluded in some e.g. NS.	No eligibility criteria for an initial needs assessment. Includes mental, physical and sensory, brain injury, autism, elderly, chronic illness. For long-term care needs to have continuous need for monitoring and supervision.

Duration of disability		Not specified	Impairment is or is likely to be permanent. Likely to require support for their lifetime (intensity may vary)	Likely to continue for at least six months		Not specified
Impact of a disability	What is the level of risk to a person's independent living, health or well-being– critical, substantial, moderate and low. Consider impact of failure to intervene	Is well-being significantly impacted i.e. unable to achieve at least 2 of a list of 11 specified outcomes	Is functional capacity reduced which affects communication, social and economic participation, learning, mobility, self-care and self-management	Limits ability to function independently and requires ongoing support	Ongoing needs for personal care and home support services (AB), unmet need in living arrangement in the community and community participation (NB), acceptance priorities based on assessed need and level of risk (SK). MB uses SIS tool	
• **Early intervention**	YES – short term support which will help reduce the need for ongoing support e.g. at crisis or transition points	Local authority have a role in preventing or delaying the development of care and support needs.	Yes if it will benefit them by reducing their future needs for support	Not mentioned	Not mentioned	Not mentioned

• **Method of assessment**		Have option of using a self-assessment system instead of or in combination with more traditional assessment methods.		Can use a self-assessment system		

* Based on analysis of 8 Provinces. Provincial abbreviations as follows: Alberta AB, British Columbia BC, Manitoba MB, Ontario ON, New Brunswick NB, Novia Scotia NS, Prince Edward Island PE, Saskatchewan SK
**Some restrictions for children
***Older people may qualify in some instances

Source: Pike et al, 2016

Table 2: Permitted Services and Supports

Criteria	Allowed	Not allowed	Pay family	Other financial information
Scotland	Employ a PA, personal and nursing care, housing adaptation or equipment, day services, short break, respite, anything that will meet supported persons assessed needs.	Residential care. Anything illegal. Direct funding not allowed if likely to put the supported person at risk.	Allowed (but carefully controlled)	Carers can request an assessment of need and may receive funded support.
England	Accommodation in a care home or similar, care and support at home or in the community, counselling and other types of social work; goods and facilities, e.g. assistive technology in the home or equipment/adaptations, information, advice and advocacy.	None stated	Unclear	Carers also receive a personal budget and a support plan
Australia	Day to day living costs arising directly as a result of their disability support needs	Anything that is likely to cause harm or pose a risk to others Anything not related to the participant's disability Duplicates of other supports being received by the same funder Day to day living costs (rent, groceries and utilities)	Only in exceptional circumstances and as a last resort, short term, and not living in same residence.	
New Zealand	Home and community support services – household management and personal care Employment of support workers Support to participate in	Day and vocational services, rehabilitation services, residential or respite in ministry	Allowed	Can chose to self-manage funds or purchase additional administrative support from

Table 2: Permitted Services and Supports

Criteria	Allowed	Not allowed	Pay family	Other financial information
	community activities.	contracted facilities, carer support, information and advisory services, equipment or housing modifications, child development services		a host provider.
-Canada - Physical disability	Personal care, home support, respite and equipment non-professional services to support independent living in the community. Employee transport (MB) Emergency back-up and contingency services (MB)	Professional services (nursing, social work, physiotherapy) (Ab)	Unclear	Allowance for admin costs (MB, ON), staff training and recruitment (MB). Financial limit not to exceed cost of long-term care funding (SK) Client contribution depending on means
Canada - Developmental disability	In general home living supports, employment supports, community access supports. Respite services for some people (AB). Funding to support self-directed planning and the administration of the funding(ON). Can purchase from a wide range of suppliers including community service providers, private services, adult education, personal support workers, family members and friends	Indirect respite services and supports such as cleaning, meal preparation, snow removal and care of other family members, housing and home maintenance, other living expenses, drug benefit, medical aids, dental are and therapies, assistive devices and specialised equipment,	Allowed, in some provinces Can be used for certain family members but not primary care giver in ON No (NS)	Client contribution depending on means in some provinces.

Table 2: Permitted Services and Supports

Criteria	Allowed	Not allowed	Pay family	Other financial information
		vehicle purchase and modifications, leases and rentals, holidays, assistive devices and personized equipment		
Canada Physical and developmental disability	Home support worker, respite, personal supports and assistance within and outside the home, supports for community involvement and participation, personal living skills training, transportation supports, technical supports and assistive devices, residential facility services. (New Brunswick)	Addiction services, vehicle retrofitting, major home adaptations or subsidised housing, mental health services, employment services, childcare services, income support, medical services or prescription drugs and residential facility services (New Brunswick)	Unclear	
Netherlands	Cost of a carer. Various customized services and general services (not specified)		Allowed	Client contributions depending on means. The cost of care at home must not exceed the cost of residential care.

Source: Pike et al, 2016

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