Research into the implementation of Resource Allocation Models

April 2017

April 2017

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# Glossary

1. NDA - National Disability Authority
2. HSE - Health Services Executive
3. NHS – National Health Service
4. SEN – Special Educational Needs
5. SEN&D – Special Educational Needs and Disabilities
6. LD – Learning Disability
7. RAS – Resource Allocation System
8. RAM – Resource Allocation Model
9. PB – Personal Budget
10. DP – Direct Payment

# 1. Introduction

This report contains the findings of a study commissioned by the National Disability Authority to consider the implications of the introduction of a resource allocation system for disability services. Currently, in Ireland, disability services are either delivered directly by the Health Services Executive (HSE, about 20%) or by service providers who receive block funding from the HSE (about 80%). The Transforming Lives Value for Money and Policy Review of Disability Services recommended:

* a common assessment method to determine the services required by an individual
* a standard resource allocation methodology should be adopted by Health Services Executive to support an equitable allocation of available resources

## Aim

The aim of this research project was to study the lessons from the implementation and operation of resource allocation systems in other jurisdictions, when used for case-mix[[1]](#footnote-1) or individualised funding, to guide the transition to and operation of a resource allocation model for disability services in Ireland. In particular, the aim was to learn about good practice in transitioning to such a system, operation and governance, critical success factors, challenges and difficulties across both types of funding mechanism. The evidence in the report reflects the weight of available evidence to the authors about both systems

The research specification was clear that lessons about particular resource allocation systems were out of scope. Instead, the aim was to look for general lessons about the introduction of such systems.

While the primary purpose of the research was to look at the operation of a resource allocation system in disability services, it was recognised that learning from the application of these systems may be transferable across the social care area.

## Methodology

This report draws on two main strands of information. Firstly, a literature review was conducted. The search was undertaken by the Social Care Institute for Excellence (SCIE) and is described in Annex B. The information specialist took an iterative search approach across a number of sources which included primary searches and further gap searching after the team had identified relevant studies from the initial search results (see Annex B and Annex C for specific search terms and database collections searched). Studies were screened (for relevance) by the team and identified studies were ordered for full text screening and potential inclusion in the review. The full literature review is contained in Annex D.

While the literature review provided a broad range of information, there remained a number of significant gaps in areas of interest to the National Disability Authority. SQW, therefore, sought to narrow its focus to a selected range of countries and local areas, and conducted a number of consultations with key experts around practice and experience in these localities. This stage of the research focused on countries where we had most information and could access appropriate consultees, and covered England, Scotland, the Netherlands, and the USA. In total SQW consulted 13 people across four localities (England, Scotland, the Netherlands, and the USA). A full list of the consultees is contained in Annex E.

The analysis which follows draw on both the literature review and the consultations. The analysis includes examples of implementation mainly from the four case-study countries. Where appropriate examples from a wider range of countries are cited as well.

## Report structure

This report consists of nine Chapters. Following this introduction, chapter 2 discusses what resource allocation models are and introduces the four case-study countries that are used as detailed examples throughout the report; Chapter 3 describes the scope of the resource allocation models in different jurisdictions; Chapter 4 covers issues relating to the governance and operation of resource allocation models; Chapter 5 discusses the role of the family; Chapters 6 to 8 detail issues around the transition to a new resource allocation model, including managing change to the system; the development of the local market and support to practitioners; service providers and service users; and Chapter 9 provides draws together the key learning points to address the original research questions.

Technical information on the research methodology, a bibliography, a full list of literature search terms note, a list of research questions, a list of consultees and the full literature review are provided in a set of annexes at the end of this report.

# 2. An overview of Resource Allocation Models

## Introduction

This chapter serves as an introduction to the discussion around the implementation of resource allocation models by describing briefly how different funding models work and some systems through which resource allocation is enabled. The study has not reviewed individual resource allocation systems as they have been the subject of other research undertaken by the National Disability Authority.

## Resource Allocation Models

A resource allocation model is an approach used to relate resources for disability and social care services to the needs of individuals. This refers to the whole system, from the identification and assessment of need, through to the calculation of a budget for each individual, to the provision of support, and later the review of this support. In many countries there has, in recent years, been a move away from contract or provider led system, which was characterised by block grants and service users being directed to existing services that, to the service user, appeared to be free at the point of use. Often the scale and levels of funding contained in service contracts have reflected past practice, with unclear links to the varying needs of the individuals covered.

To replace this approach and provide a more equitable distribution of resources, two main approaches have been introduced to deliver funding which is more closely tied to the needs of individual users:

* case-mix where a block of money goes to the provider based on their clients’ profiles, and it is up to the provider to balance resources across individuals
* individualised funding, most commonly known as ‘Personal Budgets’ where funding is allocated to each service user based on their individual need. The individual is usually made aware of the resource allocated for them and be engaged in planning how best this allocation is used to meet their needs

This change represented a move to a person centred approach as a general principle of dealing with cases. This approach focuses on the elements of care, support and treatment that matter most to the individual and their family.

The literature review found variation in the resource allocation model used at national and regional levels. Some resource allocation models were national and covered whole countries, for example Austria, Germany and France. However, each country had a different model to the other. For example, the Austrian system was based on a grid with seven levels of need, the French system had six levels of need, and the German resource allocation model had three levels (Da Roit and Le Bihan, 2010). The approaches adopted were often defined by statute, although the tools (such as the particular resource allocation system and form of support plan) were not. It was more common to find variation within countries than to find a single national framework. For example, Gadsby (2013) found that within the American Cash & Counselling pilot there was variation by state. Italy was another example where the resource allocation model used was decided locally (Longo et al, 2015) and there was considerable local discretion in Scotland and England.

## Resource Allocation Systems

The means through which needs are assessed and the budget calculated is commonly referred to as a resource allocation system. There are a range of resource allocation systems in use, and the National Disability Authority has looked in detail at four options for use in Ireland. These systems commonly included two elements:

* a tool which assessed needs, and rated or ranked them in some way
* a mechanism which converted the needs assessment in to a financial value

SQW’s experience, reinforced by consultations conducted by SQW, suggested that for practitioners and service users it was the assessment of need that was often the most transparent. The financial aspect was often less clear to people, often being based on complex algorithms (unless the financial aspect was derived based on existing or planned service use, sometimes referred to as equivalency).

## Case-study countries

One of the aims of this research was to gather learning around the implementation of a resource allocation model in different localities. Throughout the report we include examples from different countries. The literature review and consultations provided some detailed and depth information on four countries in particular, which are used as case studies throughout the report. The four countries are England, Scotland, the Netherlands and the USA. This section provides a short summary of the resource allocation model and its statutory basis in each of these countries.

### England

England adopted a national framework, but with delivery decided locally. The statutory responsibilities of local authorities and care providers in ensuring that people’s needs are met and that services promote peoples’ outcomes are set out in two key pieces of legislation the national Health and Social Care Act, 2014 and the Children and Families Act, 2014, although the system has been developed over many years. The principles for an assessment of needs are set out, and the assessment must be revisited at least annually to see if the intended outcomes are being achieved.

In England, the delivery of personal budget had begun well before the legislation was passed. The Community Care (Direct Payments) Act 1996 established the right for people aged 18-65, assessed as requiring community care, to receive direct payments (DPs) in the form of cash payments in lieu of social care services provided directly by the local authorities. This initially provided access to direct payments for adults with physical disabilities, adult mental health service users, and adults with learning difficulties. The intention was that people with disabilities could arrange their own services, choose the type of support they wanted, and how it was to be delivered. The Carers and Disabled Children’s Act 2000 extended direct payments to carers over 16 years of age, parents with responsibility for disabled children, and disabled young people aged 16 and 17.

In 2003, after the implementation of the Health and Social Care Act 2001, local authorities were required to offer direct payments to everyone eligible for social care services. To further encourage take up, the Government sought to build a strong evidence base through the Individual Budgets pilots for adults’ programme, which ran in 13 local authorities in 2006 and 2007. The extent to which people were encouraged to use a personal budget however, varied considerably across local authority areas.

The passing of the Health and Social Care Act 2014 provided the strongest guidance yet, introducing a requirement for personal budgets. It would appear that the Government passed this legislation to give weight and emphasis to the intended reforms, and to ‘tidy up’ and clarify previous legislation. What the legislation did was to:

* make it clear that people were to be offered the option of a personal budget
* describe different ways that a personal budget could be managed
* detail services that the offer would cover
* set out the timescale over which the new system had to be available to all.

Initially only people aged 18 or over were eligible for a personal budget. Since 2014 eligibility was extended to include children and young people with special educational needs and disabilities (SEN&D) and from 2015, to include children and young people with long term health conditions.

The personal budget can be:

* taken as a direct payment (a cash payment); or
* paid in to an account that is being managed by the local authority or an independent third party (chosen by the service user)

While the model adopted is defined by statute, the systems and tools for calculating and allocating the budgets are not. The systems for calculating the budget are selected by local authorities independently, and this has led to some level of variation between local authorities.

### Scotland

The statutory responsibilities of local authorities and care providers are set out in the Social Care (Self-directed Support) (Scotland) Act, 2013. The Act came into force on April 1, 2014 and placed a duty on local authorities to offer people who are eligible for social care a range of choices over how they receive their support. The personal budget can be:

* taken as a direct payment
* allocated to a provider the individual chooses (sometimes called an individual service fund, where the council or funder, holds the budget, but the individual is in charge of how it is spent)
* used to provide service that the council arranges
* a mix of all of the above

As with England, much of what was in the Act was already possible. However, the passing of legislation was expected to clarify the position and add emphasis to some initiatives already underway determined by the Government. While the passing of the Act, and the engagement that took place around it was viewed positively at the time, some of our consultees now questioned whether it was needed and if the time spent on the legislation could have been better used to promote take up within existing legislation.

The Act applies to people of all ages. The calculation of the budget is done at local authority level. That has led to local authorities adopting a range of resource allocation mechanisms, including the development of specific tools and an equivalence approach, whereby, budgets were calculated based on their individual’s use of existing services.

There was significant investment to support the introduction of the new approach. A total of £50m was invested by the Scottish Government between 2011 and 2016. This money went to local authorities to support them in developing systems and training, to encourage providers to innovate and to enhance support organisations which assist services users and carers through the system.

### The Netherlands

The Dutch adopted a national model on a statutory basis, as part of a wider long-term care legislative framework. The Netherlands was one of the first countries to implement a personal budget system (in 1996). The personal budget system in the Netherlands was universal, which posed a great financial burden on the social and health care system. As early as 2003 a Dutch academic paper[[2]](#footnote-2) had warned about the risks relating to increased burden on the social care system. Indeed, between 2002 and 2010 the number of personal budget holders in the Netherlands increased ten-fold, and problems with the system (relating to budgeting as well as people ‘gaming’ the system) were becoming evident. The system was subsequently significantly overhauled in 2012 (Beer et al, 2013).

The changes introduced in 2012 included eligibility for personal budgets being scaled back as costs were spiralling (Gadsby, 2013). This happened because eligibility was flexible and ‘largely based on trust’ (Beer et al, 2013), which increased the pool of potential applicants. In addition, cost had risen because:

* users with disabilities whose needs had not been met by traditional support services, took the opportunity to claim additional services which were more appropriate to their needs
* the level of available family care was not taken into account in assessments, which was later changed but was not applied retrospectively
* the threshold at which people moved in to residential care homes was deemed too low, and this was also changed

The system operates around eight levels of care. The changes mainly affected Levels 1-4:

* Levels 1-2 – fairly light care needs for people at home such as personal care including cleaning. This has been cut by 40%. The offer is made to people and they can purchase additional support, at reduced costs. They have also sought efficiencies by stopping nurses doing lower skills jobs like cleaning
* Levels 3-4 – people in this group used to go in to long term care, but now stay at home. The State no longer pays for housing costs, which has yielded significant savings. Hours of care provided in homes have not been affected by these changes
* Levels 5-8 – standard nursing home care. Generally, this group was not affected by the policy changes

An important part of this transition in the Netherlands was assuring people, already in care, that they would not be required to leave.

The most recent legislative changes came in in January 2015. Personal budget payments are made under the Social Support Act 2015 (which sets out the responsibilities of the municipalities to provide care for people living at home who are unable to independently arrange the care and support they need), the Long-term Care Act (which set out the national health insurance scheme. All people living or working in the Netherlands are insured under the scheme. The scheme allows reimbursement for care that is not covered by regular health insurance) and the Healthcare Insurance Act (which was set out in 2006 with the aim of increasing the quality of health services in the Netherlands. Each person who lives or worked in the Netherlands is obliged to have a health insurance) (Pike et al, 2016). The Dutch government, the health insurer and the municipalities are jointly responsible for the implementation and delivery of the resource allocation model.

### The United States of America

The Americans with Disabilities Act became law in 1990. It is a civil rights law which sets out the rights of individuals with disabilities in the USA, including protection from discrimination in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public. There are a number of federal programmes which provide services and assistance to people with disabilities. The largest programmes include:

* The Social Security Disability Insurance, which pays benefits to the individual and certain members of their family if they have previously worked for long enough and paid Social Security taxes (deeming them ‘insured’)
* The Supplementary Security Income, which pays benefits based on financial need
* Medicare or Medicaid coverage for people with disabilities, which act as health insurance coverage for all pre-existing and new conditions

The literature suggested that political and legislative decisions about the choice of the resource allocation model, the scope of services covered and methods of payments were made locally at State level. As a result, there is a great level of variation by State with regards to the resource allocation model in use, with some States adopting a personal budget model and others adopting a case-mix model.

In the USA, the legislation encourages people to remain in their homes. Residential care is generally very expensive, and the majority of people would need to pay for the service privately. This refers to care-homes in particular. Medicare may cover the cost of residential care under certain circumstances (depending on condition and financial need), however, this is not very common (Robertson et al, 2014).

# 3. Scope of the Resource Allocation Models

## Introduction

The literature review highlighted some degree of variance between different jurisdictions with regards to the models and systems adopted. This chapter discusses the scope of a range of resource allocation models, looking at what type of needs are covered and what types are excluded.

## What types of need are covered by the Resource Allocation Models?

The evidence from the literature suggested that resource allocation models (whether a personal budget or case-mix) covered a range of personal care needs, including physical, mental, and social care needs and those relating to education. They often cover all age groups, although, they tended to be rolled out by specific age groups or need.

Personal budgets have tended to focus on personal and social care. They have often been focussed on people living at home, with support provided to enable this to happen and provide a suitable quality of life. The budget was often then spent on personal support through a personal assistant, who came to the home to help with daily living needs, for example, getting up, getting dressed or leaving the home to socialise with others. The latter could also be related to offering respite for the carer, with the personal assistant taking care of the service user to give the carer a break from their caring responsibilities. In certain cases, the personal budget could also be spent on one-off purchases of specialist equipment, (for example, to help with communication), although, others deal with capital expenditure separately.

Case-mix models tended to focus on residential care services, and were most prevalent in care home settings. The budget allocated in a case-mix model could cover the cost of overheads, the purchase and maintenance of equipment, as well, as the direct cost of the service.

In theory, there should be no restriction on what a personal budget can be used for, provided that it addresses the needs / meets the outcomes of the service user as they were identified during the assessment process. However, in practice, countries and localities place varying levels of restriction on how and what the money can be spent on, specifically:

* Certain types of health services, for example General Practitioners (GPs), tended to be excluded in countries where health services were provided through a nationally subsidised health care system
* Residential care is often excluded (or at least cannot be paid for through a direct payment) in part because there is thought to be less flexibility in how this could be delivered. Indeed, many countries prefer to encourage people to stay in their own homes, for as long as possible as this is the wish of most individuals and it helps to reduce the costs of care for authorities
* The extent to which the family is relied upon for the provision of care.

## Regulation of Personal Budget expenditure

The move towards person centred approaches to resource allocation are often accompanied by the establishment of regulation and monitoring systems, in order to ensure that the budgets were being spent to meet the needs of the service users, as well as, to prevent fraud and abuse of the system (by service users, service providers and practitioners). The literature highlighted a number of monitoring approaches that have been used by different countries. While some countries operated a complex system, which required a high level of financial reporting from service users, others required only limited financial reports, and a few countries (for example Italy and Austria) running largely unregulated systems (Carr, 2011; Rummery, 2008; Gadsby 2013).

The implementation of high levels of regulation reflected the concerns that the authorities had in relation to fraud and abuse of the system by users. That said, it is important to note that, in some cases, there was a sense of misuse of the budget but not necessarily fraudulent use. Sometimes, users were unsure of the complex implicit and explicit expectations of how their budget should or should not have been spent (Beer et al, 2013; Junne and Huber, 2014). The literature did not provide any evidence to suggest that high levels of regulation assisted in reducing fraud. Furthermore, the literature did not provide figures for the level of misuse of the budgets except in England as described below.

Countries operated different payments systems. These included the use of pre-paid cards and vouchers, or payment into an account held by an independent third party. The appeal of these approaches was that they:

* allow the service users to choose their appropriate support and to say that it has been delivered and should be paid for (in the case of a managed account)
* allow case managers (as well as service users) to keep track of budgets expenditure online
* enable authorities to block the card if the user is abusing the system
* allow the authorities to see where money is not being spent, and enquire if this is because the assessment has over allocated resources or if the person is not organising their care properly

## Examples from case-study countries

### England

Since April 2015, individuals aged 16 and above requiring social care support in England, have a right to apply for a personal budget if they wish, with the local authorities having the duty to inform all eligible individuals of this right. Personal budgets for adult social care had been available for many years previous, but were promoted differently in different localities. That said, by 2014/15 the median proportion of adult social care users with a personal budget was high at 88%, with 22% of those in receipt of a direct payment. Take up of direct payments was higher amongst young adults and those with physical or learning difficulties (National Audit Office, 2016).

Personal budgets are available for the elderly, those with social care needs (physical or mental impairment), those with special educational needs, those with disabilities and those with long term (continuing) health conditions. They can be used to purchase mainstream services (for example, therapies), employ personal assistants and to pay for respite or recreational activities (e.g. horse riding) if it has been agreed that they serve to promote individual outcomes. Manthorpe (2009) even reports that someone with very high support needs can put direct payments towards the cost of buying a house.

While the scope of personal budgets in England seems broad at first, in reality, local authorities put conditions and processes in place which requires money to be used towards “specifically identified outcomes or lists of approved services or goods” (Gadsby, 2013). These conditions were put in place to ensure that the services purchased promoted the individual’s outcomes and the budgets were not being spent fraudulently.

Budgets were not used to pay for most health services including General Practitioners (as these were covered by the National Health Service). They could be used for respite care, and since 2014 could also be used to pay for permanent residential care. Service users tended to use the personal budgets to employ Personal Assistants and other forms of provision in the home. They tended to make less use of residential services, even for respite services, with people (including families with disabled children) preferring to spend time in their own homes.

England is one of the countries which operated a regulation system that required a high level of financial reporting from service users. Although this varied between local authorities, in many areas, it involved auditing of budget holders frequently (in particular, those who received their allocation by direct payments into their bank account). In these audits, users were required to provide detailed bank statements and receipts of purchases. Users were held to account if they were found to have spent their budget ‘incorrectly’ as defined by the local authority (that is, failed to make a case to link the services used to identified needs). Councils have the right to take service users to court and have done so (or settled out of court) to reclaim money which they believed had been spent inappropriately. However, demands for repayments of funds are rare.

The requirement of users to provide high level of details on their expenditure suggested that the authorities had concerns about misuse of the system by users. The Audit Commission in England recommended that social workers, in their capacity as case managers, should be trained in fraud mitigation in order to reduce the risk of fraudulent use of budgets. However, experience suggested that the levels of abuse of the system by those with direct payments was low. In 2013-14 local authorities identified 438 cases (fewer than one case per thousand), with a value of £6.3m (from a total budget of £6.3bn). Although recorded incidents of fraud during this period were few, the level of fraud was three times higher than previous figures from 2010-11. However, this increase could be due to better detection and recording.

The high level of regulation (especially around direct payments where people had to keep detailed records) created a substantial administrative burden on service users, as well as, social workers. This burden reportedly led to people opting out of direct payments. In order to address this issue, Lincolnshire County Council, for example, piloted a system to reduce monitoring to more manageable levels on both sides. The authority moved from an annual audit of the full financial reports of all the direct payment holders, to a requirement of bank statements once a year from all direct payments holders (to indicate the balance of the budget) and a full financial review of a sample of ten per cent of users annually. Additional audits could be triggered by social workers, if they had concerns about a particular service-user in their care. This new approach appeared to improve the take up of direct payments by service users in the local area, whilst the levels of fraud and abuse remained low.

Other forms of regulating the usage of funds were payment through vouchers or pre-paid chip and pin cards. This allowed the monitoring of usage as well as blocking the cards if the authorities felt that the funds were being misused. It also facilitated changing the payment duration to be more frequent and of smaller increments, to prevent users from spending their fund inappropriately if too much was paid in advance. In addition, local authorities can monitor under-spending and check if this is due to people not caring properly for themselves or not needing all of the budget, in which case, money can be pulled back.

### Scotland

In Scotland, personal budgets are allocated for social care needs across all ages. Although residential care was covered, it could not be paid for through a direct payment. This is because there was thought to be less scope to personalise the service, or at least to do so in the same way as for those who live at home. The cost of support could provide a useful decision point for where people were cared for: if the costs to cover the level of need in the home was greater than the costs of residential care, then the personal budget will be guided towards residential care and if not then they would be cared for in their home (one local authority had acknowledged this publicly). If people left a care home then they could become eligible for a personal budget, but our consultees were not aware of this happening which probably reflected on the state of health of those in care homes.

Also, excluded were reablement services, which were provided, for example, for people coming out of hospital/following an accident and who required short term support to get back to a stable way of living. The thinking here was that personal budget were better suited to dealing with longer term, more stable issues.

Service users tended to use the budgets for employing Personal Assistants and other forms of provision at the home, and this has slowed the demand for and entry in to residential services. It suggested, as with England above, that people prefer to remain in their own homes if possible.

Payment systems differed by area in Scotland. In some areas the authorities used pre-paid cards to monitor the use of budgets. In other areas the authorities carried out a risk assessment and made a decision about the duration and size of each payment based on this assessment. This was to ensure that the user did not overspend if too much of the fund was given in advance. That said, experience suggested that the level of abuse of the system by those with direct payments was low, although no figures were actually available.

Areas using online payment systems have used analysis of under-spend by individuals to claw money back that was allocated but not spent (and instead was sitting in users’ accounts). This was reported to be more common than over-spending or abuse. A considerable level of under spend could be seen as a sign of an initial over-allocation. However, it was thought more likely that it reflected service users being cautious with their allocation in case something went wrong and they needed more support later. If this assumption is correct, this would signal a need to ensure that users fully understand what the budget was intended to cover and that they were using the budget to achieve a suitable quality of life. As will be discussed in the next Chapter, monitoring outcomes would form an important part of this check.

### The Netherlands

The Netherlands used to have flexible eligibility criteria for personal budget, which were ‘largely based on trust’ (Beer et al, 2013). In addition, they had a fairly low threshold for moving people in to long term care. This caused costs to rise sharply, and what followed was a wider political push to restrict what was being funded and reduce expenditure by 25%. As a result, since 2012, eligibility in the Netherlands has been scaled back.

Long-term care was regulated by the national insurance scheme, WLZ 2015 (Dutch Long Term Care Act), which was obligatory for all residents. This covered care for the elderly, disabled and chronically sick (Pike et al, 2016).

The system in the Netherlands had conditions and processes in place which required money to be used for “specifically identified outcomes or lists of approved services or goods” (Gadsby, 2013). Personal budget could be used to pay for personal care, nursing care, support services (for example day-time activities) and short-stay respite care for holidays and weekends. Budgets could not be used for alternative treatments, medical treatments, or treatment by allied health professionals.

Furthermore, care homes were not included in the services covered by the personal budget. This rule was applied to new service users in an effort to increase the number of people staying in their own homes, with the aim of reducing system costs. Those already in care homes were assured that they would remain there, even if they did not meet the new eligibility criteria for care home support.

The Dutch system required considerable input from users, however, it was intended to enable user autonomy (Gadsby, 2013). Personal budgets were paid into an account in the Social Insurance Bank. Payments were made to service providers after users confirmed that they have used the service and approve the payment. This has been seen to deliver savings compared to more traditional block contracts, where a service was funded regardless if the service was fully delivered.

### The United States of America

In the USA there was a high level of variation between States in terms of what a personal budget could be spent on. Each State controlled the permitted range of services and equipment. Generally, all States allowed personal budgets to be spent on personal assistants and care-related goods and services. Some States allowed users to purchase skilled nursing and long-term rehabilitative therapies. Other States allowed budgets to be spent on clinical recovery services for people with serious mental health conditions. The literature did not provide information with regards to what specific user groups were eligible for a personal budget.

A case-mix model was also in use in the USA in a number of States. Case-mix models in the USA tended to focus on care-homes and residential services. The budgets covered were decided in each State (and depended on the administration in power). These considerations included the history of payments for the services (that is, what was acceptable in the past), payments for overheads, the quality of the service, the relationship with the provider, geographical location (that is, whether rural or urban), and any external factors (for example family support available) to name a few.

The system in the USA operated complex programmes which often required a high level of financial reporting from service users. For example, it required users to develop a support plan to manage their budgets, before an authority passed the budget (Carr, 2011). The system, (in theory) intended to enable a high degree of user autonomy (Gadsby, 2013).

| Examples from outside the case-study countries (Gadsby, 2013)* In France the budget could only be used to fund specific care packages or to employ a personal assistant.
* In Belgium, budgets could only be used to employ a personal assistant or pay for services from a (specified) choice of providers. At least 95% of the budget must be spent on salaries.
* In Canada budgets could be used to purchase disability-related supports. They could not be used towards the cost of medical supplies or equipment, home renovations, electronic equipment, leisure or recreation purposes, or personal / family costs.
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## Conclusions and recommendations

In the literature there is plenty of evidence of the variety of systems and mechanisms in place to offer personal budget, but very little comparative research or evaluation of one approach against another to say what works ‘best’. Therefore, in reaching our conclusions SQW have drawn on the evidence and SQW own experiences and judgements.

* Resource allocation models are most commonly used for adult social care, including those with disabilities. There are two very broad groups of users:
* Those who are able to be cared for in their own homes – and who it appears have most opportunity to alter and personalise their care packages to support living independently. This group would appear best suited to a personal budget approach including direct payments
* Those who are in some form of residential care - respondents felt that while it was possible to calculate a personal budget for this group, it has been argued that the extent of flexibility and usefulness of direct payments appears lower, although there is little direct evidence to support this view.
* Countries have commonly passed national legislation to underpin the resource allocation model. There is variation in what the national legislation specifies, ranging from a truly national system to one whereby the legislation provides a framework that is operationalised locally with a lot of discretion, for example about the choice of resource allocation system.
* Personal budgets have been used as a tool to retain more people in their own homes. This can be beneficial for the individual and reduce costs. Most benefits appear to occur where individuals are supported and given good information to make appropriate choices
* That said, although there has been the opportunity, there is little experience that offering personal budget will encourage people to want to move out of a care home if they are already there. This may reflect the nature of those in residential settings in the case studies countries and the political decision taken in the Netherlands that care home residents would not be removed if they no longer met eligibility criteria.
* Offering service users flexibility in how they spend their budget should be encouraged, so long as a link can be made meeting need and to achieving the outcomes agreed in the care plan.
* Online systems of payments appear to offer a range of benefits: they provide a ready audit trail and reduce the burden on users to keep records and therefore may encourage take up of direct payment options. However, the additional benefits which arise and potential value for money are unclear in the literature and would therefore require further research. A national system is likely to provide economies of scale over disparate local systems.
* Fraudulent use of personal budgets was generally thought to be low, although, SQW only found one set of figures to corroborate this. Therefore, while it should be a component of any payment system, controls should be proportionate and complex systems of regulation that require high level of reporting may not be necessary.
* 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.

# 4. Governance and operation of the Resource Allocation Model

## Introduction

The governance and operation systems of the resource allocation model is determined by national and local policy decisions, and, as a consequence varies a great deal between and within countries. This chapter discusses different examples of the ways in which countries have implemented a resource allocation model, including:

* the assessment of individuals
* the review process
* methods of payment

## Individual assessments

Service user assessments were the primary mechanism used by authorities for determining the eligibility of the service user for social care in the first instance. Individual assessments were designed to understand the service user’s health and physical needs (for example whether they required assistive equipment to move about, or whether they require personal assistance), their mental and social needs, and whether they have a family and social support network that could be relied upon for care.

This was sometimes co-ordinated with, and at other times followed by, a further assessment to determine the level of need and consequently the level of service provision that was required. At this point, the level of need was often converted to a monetary value. In some cases, the calculation of the budget at this stage was ‘indicative’ to enable changes to be made if greater or lesser needs were identified in the care planning stage.

### The nature of the assessment

The assessments were usually conducted in a format of a conversation about the service user’s condition and needs. One frequent comment about more personalised approaches is that they should lead to richer conversations, including reference to wider assets beyond the services which can be drawn on to support the service user. The conversation was based on a set of questions, the answers to which were used to assess the individual’s eligibility for services, which in turn fed in to the resource allocation system for calculating an indicative cost of the care package.

In case-mix models a measurement tool developed by InterRAI was commonly used (mostly in European countries like Belgium, Netherlands, and Italy and in Australia); and in various states in the USA like Arkansas, Illinois Ohio and North Carolina). The process in the case-mix model included an assessment of the individual, similar to the personal budget model. The individuals’ characteristics (that is, the type of disability and condition that the individual has), as well as, their needs and the risks associated with these were assessed. Following this, a care plan was devised and a ranking on the case-mix measure was calculated. The ranking often took in to consideration the condition of the individual and the level of care that their condition required. One of the consultees commented that the benefit of this approach was that it provided a ranking for individuals based on a set of characteristics rather than on the individual needs alone, making the measurement more objective (that is, with a rank attached to each condition as a baseline). The assessments were being carried out by practitioners and service providers in the same way that it would be done for making a decision about personal budget.

### Who does the assessment?

The literature revealed some variance between countries in terms of how assessments were managed and conducted. In most countries, the assessments were carried out by social workers or care managers. In a number of countries, the assessments were conducted by specially trained independent staff. The former approach assumes that social workers and care managers were best placed to conduct the assessment, as they knew the individuals well and were able to have an open conversation with the individual about their needs.

The need for independence and objectivity were also noted by some consultees who were concerned that if:

* the social worker was employed by the funder of the budget then they may face pressure to minimise spend
* the assessor’s organisation also provided care services, then the assessor could have an interest in directing users to their organisation’s own services

That said, there could be a risk that introducing a new person to the relationship alongside an existing social worker would add to overall costs.

The literature highlighted the difference of opinion amongst experts with regards to the best approach for conducting the assessments (whether led by social worker or trained independent staff). However, there seems to be an agreement that the assessment should be client-led and outcomes-focussed (Wilberforce et al, 2014), be done alongside the service user (Manthorpe et al, 2015) and involve both the social worker and the service user.

### Ensuring reliability of assessments

It is vital that the individual assessments provide valid and reliable information on the individual’s needs and support systems that are in place. A key concern for policy is of social workers, service users or service providers ‘playing the system’ to gain more resources. To manage this, it was deemed important that the social worker or the independent assessor conducting the assessment had both clear criteria and good training.

For social workers, care organisations and service providers, the control came through quality checks. Moderation of cases through a panel can also be useful but adds an extra layer of cost to the process. It may, therefore, be best used at the start of a new approach (to monitor its introduction) and for controversial or high costs cases where small variations could make a big difference.

Some resource allocation systems, such as, InterRai, track outcome for individuals. Therefore, expectations can be set about how far people should improve or maintain their starting position. If needs are over-reported to claim more resources, then the risk is that at review the person appears to have improved over and above what would have been expected. Hence cases or assessors can be identified for further investigation.

### Transparency of assessment and the Resource Allocation Systems

The level of transparency of the assessment process and resource allocation systems that was in use varied between countries. While in the USA, the system was transparent and information on how the allocation had been calculated is available to the public, in Belgium the authorities kept that information confidential and did not share it with service users. Most countries appeared to make the assessment process fairly clear, that is, the questions being asked and often the level of need, (such as, a score or ranking) was identified.

However, the link to resources was often less clear. This reflected that complex algorithms were used, and often those administering the assessment did not fully understand how these worked, let alone service users. What tended to be understood was that identifying more needs at the assessment will generate a higher allocation. People then, from SQW’s experience, tended to judge what they have been awarded against others that they knew. In this way the allocation of support was subject to further scrutiny.

## Monitoring and review processes

### Review of individual needs

Assessments and allocations were valid for one year. This was generally seen to work well, reflecting that personal budget have generally been focussed on people with fairly stable, long term conditions. After a year, a review will take place, which may cover:

* whether or not the persons’ needs are the same or have changed
* whether or not the person’s desired outcomes have changed
* whether or not the budget allocated was appropriate and sufficient (or more than was needed) to enable them to meet the agreed outcomes

This may lead to a change in budget allocation or in the support plan.

That said, needs amongst individual service users can change inside a year. If this happens then the assessment and allocation may need to be revisited (in most countries a review could be triggered by the social worker when it became clear that an early review was required). Understandably, this caused concern amongst authorities and service providers, and posed additional challenges when it came to developing an effective and sustainable resource allocation systems.

## Reviews of resource allocation

The majority of the countries, from which SQW have examples through our review and consultations, reviewed their resource allocation systems periodically (usually, on an annual basis) to ensure that the allocations for service users were still appropriate and can allow for sufficient purchase of services to address needs. At the same time, decisions were not based on a simple function of needs, but also included a large element of political choice about the level of resources that would be allocated overall. In practice, this meant that, although eligibility criteria did not change, the levels of support given or the range of needs supported have changed (usually with those with less severe needs being most affected and experiencing most reduction). In most cases, checks included reviews of the service user assessments, reviews of the budget and reviews of the point-based or algorithm system that was in use.

## Methods of payment of budgets

### Personal budgets model

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 Council or a third party who ‘manages’ it on their behalf, or (3) a mix of the two (Carr, 2011; Needham, 2013; Manthorpe et al, 2009). 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 (Beer et al, 2013), although, this has been less common.

Payments to the accounts of service users were made on a weekly or monthly basis, and this varied between areas, and indeed within areas based on the extent of risk associated with individual service users.

In cases where budget holders lacked capacity or preferred to have a third party manage their budget, they could use a brokerage service. In this case, the personal budget is paid to a bank account held by the brokerage service, which manages the account and pays the service providers on behalf of the budget holder. Brokerage services are organisations that provide independent advice (including through peer support) to service users and support them in managing their budget. These organisations have information on the local service providers and can advise service users about the services that are available to them and that would be suitable for their needs, based on their care plan. Where needed, the brokerage services would engage with the service providers and purchase the service on behalf of the user.

There were a number of concerns around brokerages:

* • they cost money to operate and in tight financial times many appear to have been closed
* • they were at times paid for from central funds, before personal budget allocations, with the cost deducted from the personal budget allocation, however the cost was spread across all service users, not just those who use them
* • in some cases, personal budget holders had to use part of their budget to pay the brokerage service, which then could take away from the amount of care that they could access (unless an additional supplement was paid to them, which raises issues of fairness to other users).

Given these concerns it is perhaps not surprising that support for brokerage services has reduced in England as public funding has fallen. It is not clear what impact this has had on the choices people make about how to hold their personal budgets or subsequent outcomes. In Scotland brokerage services have not developed (see later commentary) and in the Netherlands there have been problems with care mediation officers taking too much control over both managing the individual’s budget and providing their care (Gadsby, 2013).

### Case-mix model

In a case-mix model, the ranking scores that people are assigned at the end of the assessment process is allocated a monetary value. This provides an indicative budget for the care plans of the groups of individuals, for which the care provider (for example a residential care home) provides the services. Payment is made directly to the care provides as a lump sum, and they manage the budget to provide the services needed by the individuals in their care.

One expert, with whom SQW consulted, who provided advice and support in implementing a case-mix models in a number of States across the USA and Europe, commented that in many cases the payment is based on a set of political considerations (for example, history of services covered and what was acceptable in the past or the relationship with the service provider) rather than purely the care plans. Authorities can include considerations, such as, the history of payments for services (that is, what was acceptable in the past), payments for overheads, relationship with providers, quality of services, geographical location (that is, whether the area is rural or urban) to name just a few.

## Examples from case-study countries

### England

In England, individual annual assessments were conducted by practitioners from social services, education and health as relevant. Reviews were carried out more often than annually for those with short-term conditions, and similarly, in cases where an unexpected change in the circumstances of a service user occurred, a new assessment of needs could be triggered by a social worker. This allowed for the adjustment of the budget. That said, a number of SQW consultees commented that the system in England was not as flexible or as responsive as it might have been. In many cases, the rigidity of the process and the time requirements, meant that adjustments to budgets did not always happen in time to address the changing circumstances of individuals. Two approaches to costing the care plans were prevalent amongst local authorities. In the first approach the cost was calculated based on the cost of services identified for delivering the plan. In the second approach the individuals’ goals and objectives were discussed as a starting point. The set of objectives and outcomes were then translated in to a monetary value (based on an algorithm drawn up by the local authority). The budget and allocation for the individual was then calculated based on the amount of money that would be required to provide the services to help the individual achieve their desired outcomes. In both approaches an indicative budget was provided initially, and this was refined and adjusted based on the agreed plan and actual costs.

Payments were made through direct payments and managed budgets systems. In addition, around 40% of local councils in England also provided pre-paid chip-and-pin debit cards. Payments were made on a monthly or weekly basis, depending on the local authority’s decision and the level of risk associated with the individual (that is, the risk of spending too much of more money if paid in advance).

Reviews of resource allocation system took place at local authority level, alongside, more systematic reviews of the models by those organisations which have developed them originally. While it appeared that many local authorities stuck with their first choice of resource allocation systems, it has often taken time to refine the initial calculations to give a set of allocations with which they were comfortable.

The review approaches taken in England were less effective at tracking outcomes, tending instead to focus on the offer of a personal budget and payment model. While local authorities held data on assessments, reviews and budget allocations, there was little information held on outcomes. Some local authorities have used a tool called Personal Outcomes Evaluation Tool developed by In Control and Lancaster University. This is an annual, self-administered survey of service users and practitioners which covers their experience and outcomes. There were tailored tools for different services. Each local authority paid for the processing of the survey and the results were analysed at system and local authority level (subject to response rates).

The analysis of the data from the Personal Outcomes Evaluation Tool survey suggested that the impact of personal budgets on individuals and their carers was largely positive, with around two thirds of respondents saying that their personal budgets had made things better or a lot better in 11 out of 15 areas of live (including dignity and support, independence and quality of life). “Good personal budget process was regularly associated with positive outcomes”. At the same time a significant minority of people found some aspects of the personal budget process difficult. People with learning disabilities and people with mental health difficulties were more likely to report that the local authority had made things more difficult.[[3]](#footnote-3)

### Scotland

Individual assessments were the responsibility of the local authorities, and each implemented its own system. Assessments were conducted by social workers or service providers, depending on the area, and were triggered by referral from social workers. They took place annually; however, they could be more frequent if individual circumstances change.

There was some concern amongst SQW consultees that perhaps because of who conducted the assessments most people opted to have their budget managed by their provider and there was little interest in direct payments. This line of thought was reinforced by many local authorities also being service providers, and have to implement personalisation at the same time as budget cuts; and by implication being worried that service users may choose not to use their services. In addition, different pricing models were adopted to allow people choosing local authority services to receive a higher budget to cover the higher cost of council services relative to the third sector.

That said, it was also argued that managed accounts appeared to be heavily preferred to direct payments, as they offer people a way to have control over the services they use, but without the trouble of having to manage an account. A number of areas also provided pre-paid chip-and-pin debit cards. The duration of payments to users’ accounts varied between weekly and quarterly based on the extent of risk associated with individual service users. This risk was most commonly assessed by the social worker.

One of the key challenges in Scotland related to the transparency of the assessment process, in particular, with regards to linking the outcomes of the assessments to needs and budgets. One of SQW consultees commented that budget cuts have made the issue highly sensitive and caused the process to be less transparent than expected. People were able to appeal their award, but consultees reported that there was a strong expectation that the award would not change except in exceptional circumstances.

The Scottish system embarked on a process of developing a tool to provide information on individuals’ outcomes. The tool was used by some local authorities. However, this work appears to have stalled. The reasons for this stall were not clear, however it appeared that there was some level of reluctance from the Government to impose this practice on local authorities.

Brokerage services were not available in Scotland, however, these are now being considered and piloted. Stakeholders commented that two models have been considered:

* use of independent brokers
* government funded brokerage.

There was still some level of reluctance to introduce brokerage services in to the Scottish system as many saw this as taking responsibilities away from the social workers who managed the case. They also risked reducing the size of the personal budget, as the payment to the brokerage service will need to be deducted from the budget.

### The Netherlands

Individual assessments in the Netherlands were conducted by independent staff from CIZ (the Dutch Care Assessment Agency[[4]](#footnote-4)). These were based on a national assessment tool (Da Roit and Le Bihan, 2010). The assumption was that there were benefits in the objectivity of an independent assessor. The allocation system was based on tools developed by InterRai.

There were two approaches for allocating budgets to residential care services. One was based on data gathered in relation to the time a certain care task was expected to take and summing these up based on the care need of the users group to get a number of, hours of the care required; the other built on existing care hours (this approach was also found to be a good indicator of future need). The number of hours of care were then converted in to monetary value.

For service users who were living at home, following the assessment, a care plan was agreed and a budget was awarded. Budgets were not paid directly in to users’ accounts. Rather, the payment was made to providers by the Social Insurance Bank. The appeal of this approach was that it avoided service users having to handle money, which some did not want to do and others may have struggled with, but it still allowed the service user to choose their appropriate support.

### The United States of America

Similar to the Netherlands, assessments in the USA were conducted by specially trained independent staff. Gadsby (2013) suggests that the purpose of bringing in trained, independent assessors was to provide an advocate for the service users rather than an ‘objective’ assessor of need, although this approach appears to raise some risks around budget control. It was important, therefore, that the assessor understood the culture of the policy.

The USA operated a flexible budget with a great level of variation between States. For example, in Arkansas, budgets were calculated as a set price per house, written in the care plan, whereas in Florida, the figure was calculated based on previous service usage or previous care plans, where previous service usage information was not reliable. Both States adjusted the budgets to keep expected programme costs at a comparable level to former agency-based services. In New Jersey, it was the value of the care plan, minus ten percent (set-aside for support services, not defined) which was used to calculate the personal budget figure (Gadsby, 2013).

The system in the USA was transparent and information on how the allocation has been calculated was available to the public, although SQW found little in the literature to describe how this had been achieved or to what effect.

The use of brokerage, or ‘fiscal intermediary services’ was strongly encouraged in the USA as a way to support individuals with book keeping. However, in the pilot Cash and Counselling programme, in contrast, is was compulsory for individuals to undergo training on how to set up a support plan and how to recruit and train workers (Gadsby, 2013). This reflects a variable approach to brokerage, usually determined in each State.

| Examples from outside the case-study countries* In Germany, users would make an application to the agency responsible for the payments. If the agency accepted their application, they were invited to a budget conference and their needs would be assessed (Junne and Huber, 2014). Gadsby (2013) summarised the review system in Germany: ‘the wellbeing of the care recipient is reviewed periodically, and, if care is deemed insufficient, the cash allowance is withdrawn in favour of services provided by a home care agency’.
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## Conclusions and recommendations

* There is no clear evidence whether an independent or practitioner led assessment is better. In SQW’s view, a national system may be more cost effective than a series of independent system delivered locally. Also, the perception of independent assessment could be useful in managing the change anticipated in Ireland and protecting practitioner relationships with service users. This type of assessment process would most likely need to be funded centrally.
* There is little evidence on the impact of brokerages. 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.
* The assessment should take the form of a structured conversation, including reference to wider assets that service users can draw on (SQW return to this issue in the next chapter, on family support). The assessment should be client-led and focussed on outcomes.
* Service user assessments should be reviewed annually (or more frequently if individual needs change). As part of the review, evidence should be collected on outcomes that are being achieved. This will help build evidence about the effectiveness of the assessment process and subsequent delivery of care.
* The assessment should be against clear criteria, with training provided to assessors in advance. A moderation panel to review a range of assessments for consistency. should be used, at least as part of the transition arrangements, to ensure consistency.
* Experience shows that getting the resource allocation systems calculations ‘right’ is difficult. At least annual reviews of the resource allocation systems should be undertaken to adjust and correct any issues identified.
* It appears that direct payments are only attractive to a minority of service users. Therefore, it is important that there is an organisation that can hold the personal budget and spend it as directed by the service user.

# 5. The role of the family

## Introduction

The role that the family or close friends play or are expected to play in caring for vulnerable relatives is complex and varies by country. Generally speaking, the literature suggested that the family is expected to carry out two functions: direct support (care) and advisory support (budget administration). However, countries differed in the level to which family members were expected to play a role in the care of the service user, and in the extent to which service users had a choice in using family members as carers.

A number of SQW consultees pointed out the important role that the family and the community can play in providing support. In some locations this was referred to as an asset-based approach, encouraging service users and practitioners to think about what wider support was available to them through family members, friends and in the community; and then to target the use of their budget to fill gaps in this support or to enable them to access this support, (for example, by paying for transport). This chapter discusses the different approaches that countries have taken in considering the role of the family in relation to the provision of support to individuals with disabilities and long term conditions.

## The role of the family

There was some level of variance between countries in the extent to which family members were expected to play a role in the care of the service user, and in the extent to which service users had a choice in using family members as carers. In countries where there was moderate-to-highly developed formal care systems provided by the state, service users did not need to rely on family support. In these countries the care system could provide all the elements of care that the individual might require, either through residential services or through a developed market of care services, from which an individual could purchase the service they require. In these cases, if the individual used the support of their family, it was by choice. Some examples of countries with developed formal care systems included Denmark, Finland, France, and Sweden (Rummery, 2008).

In some countries, where the formal state provision is more limited (that is, under developed local market and limited government funded care services), the family is expected to provide fuller care. In these cases, the role of the state was restricted to some level of payment by way of compensation for families’ expenses (Rummery, 2008). Examples of countries with limited formal state provision include Italy, Greece and Spain, where there is a strong family and community culture and where people tend to remain at home and continue to be included as members of the local community.

## Payment for family member support

In some countries payment for family members who were carers, was allowed, but in others it was not. In addition, countries differed over which family member can be paid (for example, in some countries payment was not allowed for spouses or parents), and the level of payment awarded (that is, partial payment or benefit award by way of compensation for time spent or full payment as an employed carer).

Family members acting as paid carers could have advantages for both users and the carer themselves, particularly, in communities where it was difficult to hire suitable carers (for example, black and minority ethnic communities and isolated rural communities, Carr, 2011). Furthermore, people may be happier to be cared for by someone close to them, or happier knowing that their relatives were receiving compensation for their work. Payment for family carers may have also allowed them some freedom from the obligations of full-time care, by purchasing respite care (Carr, 2011).

## Challenges

Introducing a paid element into family care could lead to dependency relationships, across generations, (for example, disabled adult child-parent, or son/daughter-parent) and intra-generationally, (for example, between spouses). Rummery (2008), citing Ungerson (2004) suggested that paying family members “has the result of commodifying relationships and expectations, with the possibility of exploitation and abuse of vulnerable parties on both sides”. In addition, Benjamin (2001) reported professionals feeling that “familial ties complicate what should be an employer-employee relationship between workers”.

Manthorpe et al (2011) cautioned that using family carers to compensate for a lack of services “can institutionalise a system of low-paid care and make family members dependent on the service user for whom they are caring”. Moreover, an emphasis on family support could lead to inequalities in care, for example, it could discriminate against personal budget holders who did not have a family network to draw on. This depended on how the resource allocation systems operated, in particular, how far the budget calculation included an assessment of how much support would be available and delivered through the family or wider community.

The literature did not provide evidence with regards to the effectiveness of different approaches to these issues in a way that their relative merits could be assessed.

## Examples from case-study countries

### England

England had a highly developed formal care system provided by the state, however, the family was still relied upon for the provision of care. That is, in cases where there was capacity within the family to provide care for the individual, and where the individual indicated that they preferred to receive care and support from their family, this provision was included in the care-plan and was considered in the calculation of the budget.

Where there was capacity to provide support, family members were expected to provide personal care and support the user in the administration of their personal budget. However, there was no obligation for the family to provide support if the family or the individual did not wish to. In these cases, support would be provided by the state.

The general rule is that service users cannot pay (employ) a family member to provide care if they live in the same house as the service user. However, some exceptions are allowed to this, usually around issues of religion, language, or communication, and practice varies across local authorities.

However, full time carers were entitled for a weekly ‘Carer’s allowance’ provided by the Government, and there were other income support benefits that carers could apply for if their caring responsibilities affect the level of income that they could earn. Unpaid family carers could request an assessment by their local authority to see whether they were eligible for additional financial assistance to replace lost earnings. The Government operated a set of eligibility criteria for carers to be awarded an allowance, which included a consideration of the age of the carer (only those 16 or over could be eligible for a carer’s allowance), the number of hours spent providing care (at least 35 per week), whether the carer was in full-time education and the level of earning that the carer made (£110 a week or less).

### Scotland

There was limited information on the role of the family in Scotland, but broadly it was similar to the position in England. In general, the personal budget cannot be paid to close relatives. It was clear that the budget was not meant to replace or pay for care or relationships with close family members. The key exceptions were where the service user:

* is unable to find a care agency or employ a personal assistant who can deliver the services needed
* has special communication needs
* has cultural or religious needs that can only be met by a family member

### The Netherlands

In the Netherlands, the local authorities were responsible for providing care for people with physical, mental or psychological disabilities, including people with learning disabilities and the elderly. In the past, personal budget users were allowed to employ their relatives as carers. This included spouses or partners, but only if the user provided them with an employment contract (Ungerson, 2004; Arksey and Kemp, 2008). This policy along with a relaxed assessment regime (based on self-reporting and trust) led to a considerable overspend of funds as in effect the state was paying for ‘normal’ family support. It led to a deficit in the care budget.

As a result, the Dutch Government reviewed the role of the family in providing care and support. In the revised system, family members were expected to provide the ‘usual’ level care, for vulnerable individuals. This was loosely defined as the care that people would normally give to their relatives, especially if members of the same household. The support and care provided by family members was unpaid. However, family members who provide care that was considered above the ‘usual’ level could be paid through the personal budget allocation. The need for above ‘usual’ levels of care was assessed during the individual assessment, but it was commented that this was quite difficult to define.

The review process also looks at the access the person has to other assets in their community, both people and support organisations. These can then also be built in to the support plan.

How far family and wider community support are delivered was assessed in the review process.

### The United States of America

In the USA service users could choose where to get their support from (that is, family member or formal provision). There was a certain level of support that could be reasonably expected to be provided unpaid by a family member, however this was not defined clearly. Personal budget assessments calculated the level of support a user required over and above the care that was considered reasonable, and family members could be paid for the support they provided. Federal Medicaid rules allowed personal budget expenditure on ‘legally responsible’ family members (spouses and parents).

That said, the extent to which particular family members were allowed to be paid (grandparents, etc.) varied by state. Some states had a long list of excluded relations, including grandparents, grandchildren and in-laws.

| Examples from outside the case-study countries* In Italy the family was relied upon to provide informal care for their relatives. There was a reluctance at the state level to provide a formal response to the rising demand for long-term care in the country (Rummery, 2008).
* Austria operated a system of state-facilitated private care. A non-means tested benefit was paid directly to disabled and older people, which could be used to pay family members for direct care support (as well as other private carers, particularly migrant workers). At the same time, there was very little state support for personal budget holders, leaving them reliant on the family to either advise them on how to manage their budget, or to manage the budget on their behalf (Oesterle, 2001; Rummery, 2008; Gadsby, 2013).
* France operated a ‘familialist’ welfare system, which indicated a strong national ethos of family care. Intergenerational solidarity was a legal obligation in France, causing public sector support to become secondary to family care. However, family members could be reimbursed for caring for a relative. Their payment was routed through recognised care agencies in order to formalise the system and protect the carer. A report from 2010 estimated that 75 per cent of the dependent elderly were cared for by their families and 50 per cent of these carers were spouses. Eighty per cent of carers in France at the same time were aged between 50 and 70. As in Austria, state support was very limited and direct payment holders were left to rely on family members to advise them on how to administer their budget, or manage it for them (Rummery, 2008; Le Bihan and Martin, 2010; Gadsby, 2013).
* Germany operated a system of state-facilitated private care. As in Austria and France, state support for personal budget holders was very limited and users were reliant on family members to advise and help them to administer their budget (Rummery, 2008; Gadsby, 2013).
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## Conclusions and recommendations

* The literature is both clear and vague on the role of the family. It is generally clear as to whether family support is expected or paid for; but in cases where budgets include it, it is much less clear on ‘how much’ support is expected to be provided before additional funding is made available. There are also concerns about conflicts between family members and safeguarding issues.
* The assessment of individual needs should consider the availability of support from family members and in the wider community. The need for resources through a personal budget should take this wider support in to account.
* It would seem reasonable to adopt an approach where family members if available, especially in the same household, are expected to provide a level of care independent of state funding. This could apply to, say, a spouse or a child.
* 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.
* There are well documented risks around using a personal budget to pay family members, although little actual evidence (perhaps because it has been excluded in many areas). In light of the practice elsewhere it would seem reasonable for Ireland to adopt a policy on not allowing personal funding to be paid to immediate family members, but with ‘usual levels’ of care not being paid for.
* Given the limited evidence, consideration needs to be given to either: having support by family members available in particular circumstances; or running a pilot to assess the impacts.
* Reviews of the care plan and service user needs should also review the extent to which family and community support has been delivered and is providing the benefits expected.

# 6. Managing system change

## Introduction

The transition to a person centred approach and personal budget was described by a number of SQW consultees as a complete culture change for local authorities. The person centred approach introduced a radical change in the traditional relationship between the local authority and service providers, as well as, between practitioners (that is, social workers and case managers) and service users. For this reason, the relationship between the different stakeholders, the range of services on offer and the allocation of resources should be considered and managed (Manthorpe et al, 2009).

The literature review and the subsequent consultations with various stakeholders identified the key challenges in the transition process and provided a number of examples of how different areas had addressed these. This chapter discusses the challenges and practicalities around the transition for local authorities, practitioners and service providers.

## Time taken to transition to a new system

There is much to be considered in the move towards a new system. In previous work[[5]](#footnote-5) SQW has estimated that at least 12 months were required to develop systems and pathways before any new system (including pilots) can go live to service users.

The evidence in the literature and feedback from SQW consultations suggested that new models tended to be rolled out to service users at the point of their review. These tended to happen annually, and provided an obvious checkpoint in the system to review needs and agree support in a new way. This did not mean that all service users were ‘changed over’ in a simple 12-month period, but just that the review was the focus point. In practice the change to a new fully embedded system was expected to take many years as we describe below.

## Costs of transition

There was very limited evidence in the literature with regards to the cost of transition. A recent summary by Pike et al (2016) asserted that “almost all schemes in the EU have underestimated the costs of implementation, including start-up costs, unpaid care provided by families and out-of-pocket expenses. Financial risks in introducing individual budgets for health included:

* double running costs (that is, running the old and new systems in parallel)
* previously unmet need become apparent (often because users did not want what was offered before, but through a personal budget can tailor provision appropriately)
* infrastructure and working with the provider market (that is, planning is required to ensure new systems do not duplicate existing ones and that required elements are in place to enable the systems to address needs)

There was also support from many consultees for an element of transitional funding to cover costs of the time needed by organisations to develop new systems, training staff and fund the piloting and trials of new processes. Experts commented that it was important that authorities ring-fenced the funds to ensure they were directed at activities intended to support the transition process, rather than, fill in gaps in service budgets that had arisen from funding cuts.

## Piloting the new system

SQW consultations highlighted the benefits of investing in a pilot of a new system, as part of the transition process. The pilot 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. Piloting of a new resource allocation model could be done by geography (that is, local authorities), or be based around service types or user groups (for example users that are allocated large budgets). Pilots required the authorities to build in time to implement the pilot, and draw out learning from the pilot so that it can be fed in to the development of the wider roll out.

## Key challenges for service providers

The literature identified four internal challenges that service providers might face in the process of transitioning from one resource allocation model to another: staff resistance, supply of staff, finance, and legalities. These are summarised in Table 6.1

Table 6.1: Challenges during transition for service providers

| Challenges | Why |
| --- | --- |
| Staff resistance to direct payments | Perception that direct payments may reduce job security and may reduce working conditions, for example, carers employed directly by users may not receive employment related benefits |
| Difficulties regarding the supply of personal assistants (regional differences meant that this was also an enabler in some areas)  | There was a lack of capacity in some regions and the job may have become less attractive if, for example, carers employed directly by users did not receive employment related benefits  |
| Perception that care was more expensive per unit when purchased individually (lack of economies of scale)  | Leading to financial insecurity which may in turn lead to the closure of some services. |
| Legal considerations – legalities unclear and confusion regarding changing rules | Acted as a barrier to take up and led to concern amongst service providers particularly around risk and safeguarding of the individual |

Source: Manthorpe, J, et al (2011) and Ridell. S, et al (2006)

Furthermore, Junne and Huber (2014) raised concerns that direct payments deskill and fragment those providing services, because service users might tend to favour the cheapest (and as a consequence) least qualified personnel as personal assistants, preventing the development of a skilled and well-paid workforce. The literature highlighted concern that this shift might have served as a catalyst for a development of a ‘grey market’ of social services, as users sought to stretch their budgets. Concerns were also raised about the role of practitioners in the local authority level. The changes to the system led to an inevitable change in the roles of various practitioners (primarily commissioners[[6]](#footnote-6) and social workers). For instance, while in a centralised system the role of the commissioners was to identify suitable service providers and commission their services for the eligible population, in a person centred resource allocation model their focus should have shifted to developing a local market from which service users could purchase services independently.

Consumer-directed services could be seen as a threat to social worker jobs and consequently staff could feel threatened and in turn, trade unions could be resistant (Arksey and Kemp, 2008). In a person centred system, the role of the social worker or case manager would change from making the decision for the individual about which services they would use, to supporting the individual in the process of making a decision for themselves about their care plan and the services they would purchase. SQW consultees highlighted two key challenges that were associated with this. The first was related to a gap in the skill-set that social workers had, which could happen with the change of their role. The second was related to the perception of social workers, who may have viewed the change as diminishing their role and reducing their responsibilities.

## Supporting practitioners and service providers through the transition

Changes in systems, whilst important and needing attention, were not expected to have the full desired effect unless culture change had been addressed. Feedback from SQW consultations suggests that supporting practitioners and staff in grasping and realising the change in culture and ethos which underpins the new system had often been underplayed.

To ensure that the transition to a person centred system is successful, it was recommended that front line staff should be involved from the outset (Manthorpe et al, 2011). Social workers and other practitioners should be reassured that their role was changing and not diminishing, and that they should have had a role in designing the new processes for the new system (in particular individual assessments). It is thought that if staff understand the reasoning behind the changes, then they are more likely to buy in to the change and deliver what was expected.

In order to ensure that practitioners could fulfil their new roles effectively, it was recommended that authorities should undertake workforce development by providing suitable training and support systems to practitioners to help them acquire the necessary skillsets and have all the information they needed to respond to different service-users’ needs Ridell et al (2006) found that training for social workers and support staff varied by local authority and was more effective in areas with a “designated officer or champion”.

## Examples from case-study countries

### England

Transition into the new system in England occurred in two different processes and points in time for adults, and for children and young people. Personal budget for adults were in operation in England well before the legislation was passed. The statutory requirement of local authorities to offer personal budget to all adults in social care was set out in the health and Social Care Act 2001, and came in to effect in 2003. Following this, the new system was piloted in thirteen local authorities in 2006-7. The extent to which people were encouraged to take up and use personal budget however, varied considerably across local authority areas. The Care Act 2014 required that by April 2015 all adults in social care should be offered a personal budget, although by this time the vast majority of services users already had one.

With regards to children and young people, Government guidance asserted that local authorities should ensure that young people with special educational needs and disabilities who are in further (post-16) education or training were transferred in to the new system (of integrated care plans) within two years of the start of the implementation of the reforms, following legislation in 2014. All other children and young people were to be transferred in to the new system by 2018. Newcomers were to be covered immediately.

The Ministry for Health awarded local authorities that were pilot or demonstration sites extra funding (£520 million during 2008-2011) to assist with the councils ‘transformation’ to personalisation (Needham, 2013). Additional monies were provided to support the SEN&D reforms for children and young people: 31 local pathfinders[[7]](#footnote-7) were each awarded an initial £225k, which was then increased; a programme of support grants was offered to the voluntary sector to help them deliver activity across several areas; and a national support team was appointed to work with local areas in developing and sharing good practice. The costs of transitioning young people from the previous to new systems are still being supported, with a total allocation to local authorities of over £30m in each of the last two years, and continuing for the next two years as well.

In some local authorities in England there has been evidence of staff resistance to this change. Carr (2011) suggested that staff should be properly supported to be a part of the transformation, be encouraged to communicate their experiences, and funding should be ring-fenced, to ensure that real systematic change is achieved. The level of support (in terms of information, training and inclusion in the change process) that was provided to practitioners during the transition varied greatly by area. The support that was provided demonstrated the level of acknowledgement among authorities of the magnitude of the change for the practitioners (that is, recognising that this was a culture change).

### Scotland

The Scottish Government expected transition to take place over a 10-year period. The vision for change was set out in 2010, following which there was wide ranging consultation and engagement; legislation was passed in 2013 and came in to force in 2014; and the system is expected to be fully operational by 2020. The Scottish Government recognised there may be a need for short-term funding to help councils make this shift in spending and transform how they delivered social care. It provided short-term funding of £42.2m for 2011-14, of which £24.9m went to councils over a four-year period. Much of this money went on additional staff to cover the work involved in setting up a new system while delivering the existing one. As part of this, each council had to appoint a local champion to lead on the changes. The remaining money was used to provide training, information and guidance to users, carers, providers and professionals.

The literature suggested that this transitional funding was “a helpful spur for innovation” (Manthorpe et al, 2011), as it had allowed local areas to test out approaches and models, and to in effect have a period of double running in the market place so funders and providers could begin to see what would be needed in a relatively safe environment.

Concerns were raised by SQW consultees that while resources were made available in advance of the legislation coming in to force, which was generally welcomed, there were two risks:

* that the money and staff recruited were used to cover revenue shortfalls and not for investment, which was possible as funds were not ring-fenced
* there was some lack of clarity about legislative requirements and so councils put off investment spending hoping more would be clearer later (but had spent the money in the meantime).

The literature review did not provide evidence in relation to managing changes to the system in the Netherlands or the USA. In addition, there was no evidence from countries outside of the case-study countries.

## Conclusions and recommendations

* Change should be introduced over a fairly long period of time, and ideally include an element of piloting.
* The pilot needs to be able to operate for long enough for the lessons learned to be fully understood and before full implementation.
* Allowing for the pilot a period of three years might be required to introduce the new system and have it operating for new service users, and a further number of years would then be required to transfer existing users to the new system. This is most easily done around standard review points.
* If the transition is to be a success, services and frontline staff should be involved and receive appropriate training from an early stage. They should also be engaged in designing how the new approach will work in their area.
* Training and development has to cover both the mechanics of the new system and the cultural change involved.
* There is likely to be a need for additional financial resources to introduce the new system to cover the development of new systems, staff training and support to service users. Indeed, most areas appear to have under-estimated the cost of change.
* Any budget provided for transitional costs, including training, should be strictly ring-fenced.

# 7. Development of the market

## Introduction

The consultations with various stakeholders highlighted that one of the main challenges with the move to a personal budget model was the requirement to develop a local market in service provision. In areas where a central commissioning model was implemented there was often one primary provider of services, and the contractual nature of the relationship between the provider and the authority meant that there was little room for other service providers to enter the market. With the move to a person centred approach, a gap emerged as there was a lack of choice on offer from different service providers. Consultees commented that it had been assumed that the local market would develop naturally as the demand grew, but in reality, this process was not as straightforward and required a greater level of intervention than envisaged to shape markets

Some of SQW consultees suggested that it should be the role of the authority and local commissioners to support the development of a local market of services. They believed that an open market for providers to come forward and offer their services should be encouraged, with the authority playing a role in making information on services available to service users, so that they can exercise their right to choose. This chapter discusses the various considerations for areas in developing the local market and provides examples of approached that have been taken.

## Effect of the transition on the market

There was concern in the literature that there were too few examples that the social care market was changing and becoming more innovative in response to personalisation. This was, as summarised by Rose (2009, in Newman, 2009): “many of the social care products available are the traditional products (for example residential care) and there is little point in controlling your own budget if all you can buy is what you would have got under the old system”.

Change was regarded as necessary to ensure that the market was supporting a more personalised approach. Although, the introduction of personal budgets had led to new entrants in the market, some existing providers were slower to innovate and change their practice and respond to personalisation. Gadsby (2013) identified that it would take service providers time to change their attitudes and ways of working. For example, the evidence from the literature suggested that the market for and supply of skilled personal assistants has not responded as quickly as some had hoped. This raised “concern about the extent to which local authorities are shifting quickly enough into their new role as market shaper rather than commissioner of services” (Needham, 2013).

There were also some concerns about the future of care homes, which catered mainly for older people. These were seen not to be popular (as people would rather be in their own homes and independent) and expensive. Similar concerns were raised about residential respite services. If respite care is increasingly delivered while people stay at home, demand for respite beds will fall. For individual users this may be good, as they get a service that they prefer, but changes in demand could also mean changes in the offer available to others, and result in diminishing choice. Providers would need to manage their business to respond to changes in demand. This included adopting new marketing and invoicing systems to deal with Personal budget and direct payments, as well as, potentially new services if that was what service users wanted.

## Ensuring the quality of services

The development of an open market, in turn, raised the issue of ensuring the quality of services. Traditionally, care would be provided by a care worker employed by a licensed and certified home care agency. The home care agency would be required to take action if there were concerns about the care given by one of their employees which was a mechanism for quality assurance. However, consumer directed support purchased with a personal budget, may remove this quality assurance mechanism if care was not purchased from a home care agency (Benjamin, 2001), in the extreme passing responsibility to the service user to terminate a contract if they were not happy and to find another provider.

This raised issues relating to the level at which the authorities can and should regulate services that are being purchased privately. It brought a number of challenges for the local authority, in addition to the possible conflict of interest if it was also a service provider. It had to balance the need or desire to:

* attract new entrants and encourage new services
* set quality and safeguarding standards, including how far it should have an ‘approved list’ of providers or simply let service users choose as they wish
* allow service users the ability to choose providers and decide what standards are important to them
* ensure cost effective provision was available, but keep spending at the same level – leading to concerns about economies of scale and value for money
* ensure employment standards.

Different approaches have been adopted, with some opting for relatively low barriers to entry to encourage new entrants. This was seen to have been done more often where there was a clear shortage of supply and choice, but interestingly it appeared to have worked quite well and with few quality concerns arising at a later stage. The literature would also support a more relaxed approach to regulation (see Annex D for the full literature review).

A number of SQW consultees suggested that the assessment of the quality of services should be a joint responsibility between the authorities and service users, and that some regulation is required. It was suggested that the authorities should put in place a set of relatively basic standards (that is, is the service safe, licensed and legal) which would act as a minimum threshold, but at the same time would not constrict the development of the market. The authority would then compile and advertise a list of approved service providers, based on them passing the standards threshold.

The list of approved service providers (the local market) would be made available to service users through various local channels (local authority websites, social or care workers, support groups, charities, etc.). The service users would then verify the quality through use and ‘voting with their feet’. The authority should work with user based organisations to develop mechanisms (for example, forums and notice boards) where service users can advertise and share their feedback on providers they used, to help others make their choice. This raises the issue of risk management and safeguarding of users, which is discussed further in Chapter 8 below.

## Examples from case-study countries

### England

The transition in to personal budget and direct payment in England has caused concerns for the future of a number of services, in particular day-care centres, respite care and care homes, as people seemed to have increasingly used their budget to access personal care support. Day-care centres were usually in receipt of block funding but day-care workers (Unison members, across England) reported centres closing or changing their eligibility criteria following the introduction of personal budgets. For example, some centres were restricting access to self-funders, care home residents, and people who did not regularly attend. Centres also started charging users, either to cover the cost of refreshments, transport, or to cover the cost of the day. However, it appears a number of personal budget holders chose not to spend their budget on the centre, but spent it elsewhere. Therefore, the effect of personal budgets on services is two-fold – first services start charging for things that had previously been included in the care package and second because of the withdrawal of some users the service sometimes became uneconomic to deliver to the remaining users. Therefore, the service may cease even for people who were happy with the service. At the same time, the recruitment of personal assistants has proved to be quite challenging. It was particularly challenging in affluent areas and commuter belts where there was already a lot of domestic support work, or in areas where large-scale employers (such as, a call centre) have recently set up (Ridell et al, 2006). Furthermore, recruitment in rural areas could be difficult because service users were reluctant to hire someone from within their small community who was likely to know them as the labour market is smaller. This meant service users opted to recruit someone from outside their community, and this involved them needing to travel in to help the individual thus increasing costs (Ungerson, 2004; Arksey and Kemp, 2008). However, people on low salaries were often reluctant to travel far. This has led some rural areas to look more to family and community based models.

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.

One example of this approach, the ‘Service Gateway’, was piloted in Lincolnshire County Council (Rowlett, 2009). 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. Feedback on users’ experiences was shared in local user forums. Feedback from users, practitioners and service providers in the area suggested that this approach has worked well in enabling the local authority to develop a diverse market of good quality services, which provided a sufficient level of choice for users.

Over time, efforts to develop the provider market have become meshed with pressures on budgets (NAO, 2016). This has led to a number of practices which appear less than ideal:

* Some local authorities seeking to appoint a smaller number of providers, in the expectation that they will then offer a better price due to economies of scale and that it will reduce the options for staff to move between providers and bid up wages
* Offering contracts at prices which are the equivalent to those paid to in-house services minus overheads. Many providers have found this unattractive and some have left the market
* Setting direct payment awards below the rate of the personal budget. This could be seen as both an expectation that the individual can negotiate a better deal than the authority and a way to encourage individuals to continue using local authority services

### Scotland

In Scotland, authorities adopted a range of approaches to develop the market, with some appearing more concerned about this than others. For larger authorities with large in-house provision there was perhaps an incentive to keep people using these services. Indeed, the funding system was set up in this way, with in-house services funded at a higher rate than private or community services. The pressure on costs generally has led some smaller providers to withdraw.

In smaller, often more rural authorities a more developmental approach was taken. This included seeking to encourage new providers to the market by offering fairly open framework contracts, with quite simple quality checks; and trying to shape the market so that providers focussed on specific areas to ensure that residents have a choice of two providers, which would also mean that the providers might gain some economies of scale.

There has been a shift away from residential care, including respite care for young people. One area reported a fall of up to 50%. That said, the overall annual churn from one provider to another, once the initial plan was in place was reported to be very low – around 2% - suggesting that people were either broadly happy with the service that they had chosen or were risk-averse.

### The Netherlands

In the Netherlands the transition was smoothed through an assurance that those already in care homes would not need to leave if they did not wish to (there is no suggestion that these care homes were congregated settings). However, the threshold was changed to try to keep people in their own home, only entering a care home later in their life as their condition deteriorated further. In time, it was hoped that this would lead to fewer people in care homes, which would undoubtedly have effect on the future of care homes in the country. The transition was likely to be brought about by a reduced flow in to homes, before a new norm was reached in several years’ time.

In 2013, there was no official system to supervise the quality of care as the underlying assumption was that “budget holders will make up their own minds about quality” (Gadsby, 2013). It was assumed that those in receipt of care would be likely to judge the quality of the service they received based on the level in which the service was appropriate, adequate, comfortable and secure. Professional standards were thought to only have limited impact on service users’ assessment of quality (Benjamin, 2001).

One outcome of the new system in the Netherlands was that previously inefficient providers were squeezed out of the market. This came about as flat rate funding made those who were inefficient (for example with out of date recording or scheduling systems to manage the utilisation of staff) either cut their service offer or charged more to cover their additional administration costs. This created an incentive for users to seek other, more efficient providers. In practice this led to some major providers failing, but with their service users then being supported by other providers. This was a significant market adjustment, but one which was thought to offer better value for money. SQW consultees reported that Government was able to use the application of the resource allocation systems as part of its defence when concerns were raised about the impact on the provider market.

### The United States of America

There was no evidence in the literature for the USA with regards to local market development and approaches to quality assurance. In addition, there were little evidence from countries outside of the case-studies.

| Examples from outside the case-study countries* In Finland the authorities operated a high level of control over the scope of the market, through inspecting and approving service providers. Budgets could only be used to purchase services from the list of approved suppliers. This had implications on the degree of choice and autonomy that could be exercised by individuals (Gadsby, 2013).
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## Conclusions and recommendations

* The change to personal budgets can have significant implications for providers. People do appear to move away from care homes and day centres towards more flexible, personal assistants
* This may create cases where some provision becomes uneconomic. This needs to be monitored to ensure that at the aggregate level there is sufficient supply. This may involve the managed closure of some facilities and the transfer of users to others
* Some providers may be exposed if they are offering services at a higher price / inefficiently, although political decisions can be taken to protect some provision. The experience of the Netherlands is that efficient providers can respond to fill gaps left by less efficient ones.
* With the move from centralised and block contracts commissioning into personal budgets, authorities need to develop a local market of services, offering a choice from which services can be purchased. The market will not develop on its own simply by users’ demand, especially as pressure on budgets can mean the market is not attractive to new entrants. Therefore, funders of the system need to undertake market development if service users are to be offered real choice
* New providers can be attracted by framework contracts which set fairly low barriers to entry, and this appears not to pose a major risk to quality (however see the next chapter for safeguarding issues)
* 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
* Relevant authorities have a key role to play in promoting the choices available to service users. This could include directories or online lists. There is limited evidence that increasing the level of choice created greater widespread innovation in services, however some anecdotal examples of individual use of budgets do exist (for example purchasing a caravan to spend time away with the family).

# 8. Managing transition with service users

## Introduction

The move to a person centred system was intended to present new opportunities and a greater level of choice and control for service users. But, at the same time, this change posed considerable challenges as well. Service users found themselves needing to navigate through various service providers in the process of developing their personal care package, and some needed to take on a new role as employers. In addition, direct payment holders needed to understand the administrative elements that were involved in the financial management of their accounts. In some cases, users found that they needed to cope with the resistance of staff, who had not engaged fully with the new system. This chapter discusses these challenges and some of the mitigating steps taken by authorities in the different countries to support users in the transition in to the new system.

## Supporting service users

Feedback from SQW consultations suggested that service users should be supported through the transition process, by being provided with information on the changes to the system that were taking place, and the implications of these changes for them. They should also receive information on the services that are available in the local market, so that they can make an informed choice in designing their care package. Finally, where budget holders lack capacity, they should receive help and support in managing their account.

The evidence in the literature suggested that support and advice to service users came from different sources: counsellors (in the USA), social workers or other relevant authority practitioners, service support staff, third sector organisation or support brokers. Ridell et al (2006) found that the move towards personalisation was leading to new user-led support groups and community-based organisations as well. These organisations raised awareness of opportunities and were thought to be a positive new source of support. That said, the austerity agenda in Europe and the USA has reduced the funds available to support such organisations (although the impact of this change was not well documented as it is fairly recent).

## Risk management and safeguarding

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 some of 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.

Adult safeguarding is not the same as child protection. Adults may need advice and support to enable them to make their own decisions and statutory services have a duty to ensure that vulnerable adults are appropriately protected from harm or abuse regardless of the funding model. 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. Research highlights that person-centred planning leading to the care package was perceived to be the key to balance safeguarding with allowing people control over their lives. At the same time outcomes for people with disabilities must be monitored.

### Approaches to ensuring safe-guarding

Feedback from our consultations suggested that authorities tended to exaggerate when discussing issues around risks and safeguarding. Evidence from the literature and from our consultations suggested that personal budget and direct payment holders were no more at risk then they were when using a previous system. A recent report from the National Audit Office in England reported that there was no increase in reported abuse or neglect of individuals since the move to the new system (National Audit Office, 2016). It was the opinion of a number of SQW consultees that the issue of safeguarding should not be a greater consideration in the new system.

SCIE (2010) and Glasby (2011) 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 can be managed in multiple ways: 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. 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 (Mitchell et al, 2012).

SCIE discussed the notion of ‘Risk Enablement Panels’, to offer a way of helping with challenging or complex decisions that may occur as part of the support plan validation process. The aim of the Panel would be to reach a decision which is made collectively, transparently, and encourages positive risk-taking. The panel should include the individual and / or their advocate; personal carers (if appropriate); independent chairpersons; Local Authority safeguarding lead; relevant multidisciplinary staff; and relevant specialists. That said, it is recommended that risk enablement panels should only be used in exceptional circumstances (SCIE, 2010).

## Roll-out of budgets amongst users

The general trend across countries has been a slow roll-out of personal budget at the start, followed by an increase over time as people become more aware of the opportunity and both users and relevant authorities have increased confidence in the approach (National Health Service Confederation, 2009). In Belgium, for example, the number of new budget holders was strictly controlled in order to prevent spiralling costs (Gadsby, 2013). In other places a slow roll-out was evident amongst specific groups as the suitability of personal budget for some user groups, such as dementia patients and the elderly, has been called into question (Gadsby, 2013).

In the case of families looking after disabled children, it has been suggested that carers were simply not aware of the scope of available services or how much they might cost (Thom and Prabhabkar, 2010). However, this highlighted the need for widely available and accessible information, advice and support for service users thinking of transitioning to a personal budget, including an explanation of how the administrative processes worked (Manthorpe et al, 2011; National Health Service Confederation, 2009).

Experience has shown that users have tended to prefer the option of a managed budget to the option of direct payment. Our observation of the cases England and Scotland and feedback from consultees suggested that peoples’ choice was influenced by the way the options were presented to them (that is, whether highlighting the benefits or the risks to the user) and by the nature of systems that were set up, as well as the capacity of individual service users.

## Examples from case-study countries

### England

In England, advice and information to users about services that were available in the new system was provided by social workers or brokerage services. The level of information and transparency of the system varied by area and was dependent on the quality of the training and support that was provided to practitioners. Even where brokerage existed, Gadsby (2013) found that users tended to look for free support brokerage from professionals they already knew, rather than pay for professional support brokerage.

Take up of personal budget tended to be low during the initial stages of the roll-out. Low take up was partly due to a lack of demand from service users (Carr, 2011). This could have been for several reasons, including: a perception that the administrative burden of a personal budget was too great; users (or carers) not wanting such a high level of responsibility for their services; or concerns that personal assistants were either hard to hire, or put stress on family relationships (if the user did not want to hire a relative) (Manthorpe et al, 2011).

Current data suggests that around 88% of service users in England have a personal budget. Around 22% of those with personal budget receive them as direct payment, and the majority use managed budgets. Those aged under 65 in England were four times more likely to use direct payment than older people (National Audit Office, 2016).

### Scotland

There was wide consultation around the introduction of the legislation. This involved user led groups, and was widely welcomed.

Take up of direct payments in large cities in Scotland tended to be low, as users have tended to stay with local authority services. The city local authorities tend to have large in-house departments which provide care and so it was suggested, as described in the section on market development, may have had some interest in maintaining demand for their own services. In rural areas take up tended to be higher where there were fewer council services and people relied on the assistance of personal carers.

### The Netherlands

There was no evidence in the literature for the Netherlands with regards to managing transition with service users.

### The United States of America

In the USA pilot 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 (although the extent of the training that was required was not specified). Furthermore, 93% of users in the programme accessed a ‘fiscal intermediary service’ to help with book-keeping. The Cash and Counselling programme is a pilot programme in three states and the numbers participating is quiet small.

Gadsby (2013) found that there was ‘considerable local variation in the ways programmes were implemented’, which affected take-up. However, he does not provide additional detail in the document about the nature of the variation.

## Conclusions and recommendations

* Service users should be supported through the transition process, by being provided information on the changes to the system that are taking place, and the implications of these changes on them
* Practitioners are trusted by service users and can be a useful source of information. However, they may have a varied interest in promoting some services over others, depending on the wider role of their organisation. User led organisations may be better placed to provide independent advice
* Service users also require access to reliable, up to date information about services available. This can be done through directories or online. It is likely that better support and information will lead service users to make more appropriate choices
* The extent of take up, especially of direct payments, is likely to be influenced by the expectations put on service users around administration, by their satisfaction with current services, and by the way direct payments are explained to them
* Safeguarding approaches need to be put in place, although these should be proportionate and probably at a similar level to what is currently in place.

# 9. Key findings and implications

The literature provided a fairly high level overview on many aspects of the implementation of a new resource allocation model. It was quite clear from our research that a wide range of resource allocation models were used across the different localities. However, it was not clear which, if any, worked more effectively or indeed which elements influenced effectiveness. Furthermore, there was no clear sense of the added costs related to the transition process nor to the on-going delivery, as questions about cost were wrapped up in wider spending decisions.[[8]](#footnote-8) While the consultations with stakeholders, who are experts in the policy area or practitioners, assisted in providing a deeper understanding of the practices in different localities, there remain gaps in the evidence base. This reflects the knowledge of individuals and a general lack of detailed evaluation studies (as they are often based at the level of the system overall rather than around individual elements), both of individual localities or compare different models either in a single or across locations.

In light of this extensive yet still limited evidence base, SQW has sought to identify key messages across a range of different contexts, taking more confidence in findings where they have been reports in more than one situation. In addition, we have drawn on our own experience to interpret the emerging findings and provide a series of pointers. The pointers are set out at the end of each chapter and are summarised and developed below against each of the groups of research questions posed (see Annex C). To assist the reader, we have reordered these slightly, but the section headings remain unchanged.

## Individual assessments

A range of staff are engaged in undertaking assessments. This can be social workers or care managers who have known supported the individual over time or someone who is independent and not known to the family (for example in the Netherlands staff are employed by an independent agency). There is no clear evidence whether an independent (at scale where the person doing the assessment has no direct financial interest in the outcome) or practitioner (social worker) led assessment is better.

In our view, with a national system it may be more cost effective to run an independent system at scale, than if this was delivered locally. Also, the perception of independent assessment could be useful in managing the change anticipated in Ireland. It could protect the relationship practitioners have with service users, being clear it was focussed on their needs and avoiding the tensions that can arise around resource allocation.

The assessment should be against clear criteria, with training provided to assessors in advance. The assessment has to cover two issues, which can be, but are not always combined: is the person eligible for support; and how much support should they receive. It would appear more cost effective to combine the two, but the former may require greater care expertise and so lean towards the practitioner model from the paragraph above.

Service user assessments are usually reviewed annually (or more frequently if individual needs change). The assessment should take the form of a structured conversation, including reference to wider assets that service users can draw on. The assessment should be client-led and focussed on outcomes, involving a range of people who can bring expertise and insight on the clients need. This will include health and social care professionals along with family members.

The output can take two forms: an assessment of need, which can be both descriptive and where it feeds directly in to a resource allocation system a series of scores; and a care plan which details the support to be provided. Although much of the case for personal budget was based around giving the service user the power of the consumer and so it was argued that they should know the budget before agreeing the care plan, there are examples where the care plan is agreed and then its value calculated. There is little evidence to say which is better.

The amount derived through the resource allocation system is not always guaranteed, nor indeed is it necessarily a cap. In England it 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. The need for this flexibility has been reinforced through case law.

## Data

The outcome of the assessment is usually held at an individual level by the funder. This is important for them to be able to review individual cases periodically and have consistent information of care needs on individuals if staff change. It should also help to provide an information resource which can be used to assess how needs are changing (outcomes are being met) over time. However, from the literature review and consultees it appears the use of data to monitor outcomes does not happen regularly, representing a missed opportunity.

## Transparency of the resource allocation

It appears that many systems will make service users aware of their personal budget. This is particularly the case where the budget is calculated on the basis of individual need, and the individual is involved in deciding how it should be spent. In these cases, there would be no automatic communication of the budget information to the provider. Instead, the individual would seek support using their budget, at which point they may choose to say how much they have to spend.

It was less clear that this transparency carried in to a case mix model. In these cases, a total amount was allocated to providers based on the mix of cases they were dealing with. It was for providers to manage this budget across service users. It did not appear that service users would be aware of the budget allocated specifically for them

## Integrity of the assessment process

The integrity of the process is dependent on the skills and confidence of the person doing the assessment, and the checks put in place. Training for staff is important to ensure that they are able to implement the resource allocation system consistently and to work constructively but if necessary also challenge service users about the extent of their needs. In practice, this is also supported by:

* Moderation panels – as described below
* Algorithms which seek to identify outliers – for example in terms of the agreed budget against the level of needs, or across different assessors, or changes in budgets/needs by individual over time.

## Scope of the resource allocation system – what is monetised

Resource allocation models are most commonly used for adult social care, including those with disabilities. The care package provides an indication of hours per week required and how this can be met, including support, personal care, nursing, daytime activities and treatments. In theory the budget can be used for alternative therapies and one-off items, although medical costs are usually excluded. In SQWs opinion, there should be clarity on what is included and excluded in the budget from the introduction of a resource allocation model.

There are two very broad groups of users:

* Those who are able to be cared for in their own homes – and who it appears have most opportunity to flex and personalise their care packages. This group would appear best suited to a personal budget approach including direct payments.
* Those who are in some form of residential care. Some countries, such as the USA, explicitly exclude this group from personal budgets as the view is that they have a limited ability to self-direct care. While it is possible to calculate a personal budget for this group, the extent of flexibility and usefulness of direct payments appears to be lower because elements of the budget such as staff costs and hours are non-negotiable (although there is little direct evidence for this assertion).

It was reported that in some places there is a limit on the value of a personal budget, and that if the value exceeds the costs of residential care than residential care will become the default option.

## Systems for non-standard needs

Personal budgets appear to work better for people with fairly stable needs. In such cases, a care plan can be agreed and implemented and reviewed annually. Where needs are unstable then there are significant issues with the model not least because reviews are costly and can take time to implement.

There can also be cases of exceptionally high need, where there is a need to adopt a more tailored approach to ensure access to a sufficient level of care supports. In these cases, the resource allocation system may not provide a sufficient resources and so a more bespoke approach is required.

## Administration

As seen in the country reports above: countries have commonly passed national legislation to underpin the resource allocation model. There is variation in what the national legislation specifies, ranging from a truly national system to one whereby the legislation provides a framework that is operationalised locally with a lot of discretion for local managers, for example about the choice of resource allocation systems. The methods that underpin allocation systems tend to be bespoke, with algorithms developed to produce a level of payment which is seen to correlate to need. The values attached to this are derived locally based on available budgets and past practice.

It does appear however, that it is usual for a single resource allocation system to be used within each geographic area, however the latter is defined

The amount of money allocated through the resource allocation system to individuals will change over time. This can reflect both the changing needs of the individual and changes in funding allocation. These latter decisions will include issues such as inflation, but in practice it appears that the decision is often a political one based on wider budget settlements.

## Appeals

Experience shows that getting the resource allocation systems calculations ‘right’ is difficult. They often seem to work slightly differently for different client groups and struggle with very high needs. As described above, for people with very high needs there are examples where a limit was put on the amount that can be allocated through a formula based resource allocation system, and instead a cost is developed based on a plan that is developed and deemed appropriate.

Given the challenges involved in developing a ‘fair’ resource allocation system at least annual reviews of the resource allocation systems should be undertaken to adjust and correct any issues identified as they arise. Moreover, a moderation panel should be used, at least as part of the transition arrangements, to ensure consistency across different assessors. This would include senior managers who would review examples of assessments and budgets to confirm that they were comfortable that the system was operating equitably.

## Transition from block funding to personal budgets

In SQW’s opinion change should be introduced over a fairly long period of time, probably five years plus. Time is required for staff to be trained and become comfortable with the new system; and similarly for service users to learn about and adjust to the new models. There is also a resource cost in transitioning people from one system to another, especially as the first review under the new system is likely to require additional resources (see references to costs in England and Scotland earlier).

Ideally, an element of piloting should be involved. The pilot needs to be able to operate for long enough for the lessons learned to be fully understood and operate before full implementation. In our experience, allowing for the pilot a period of three years might be required to introduce the new system and have it operating for new service users, and a further number of years would then be required to transfer existing users to the new system. This is most easily done around standard review points.

If the transition is to be a success, services and frontline staff should be involved and receive appropriate training from an early stage. They should also be engaged in designing how the new approach will work in their area. Training and development has to cover both the mechanics of the new system and the cultural change involved.

There is likely to be a need for additional financial resources to introduce the new system. Indeed, most areas appear to have under-estimated the cost of change, although there is little evidence on the scale of this underestimation. Any budget provided for transitional costs, including training, should be strictly ring-fenced.

People do appear to move away from care homes and day centres towards more flexible, personal assistants when offered individualised payments, particularly if the services are offering older forms of provision. This may create cases where some services become uneconomic. This needs to be monitored to ensure that at the aggregate level there is sufficient supply of appropriate services. This may involve the managed closure of some facilities and the transfer of users to others.

Service users should be supported through the transition process, by being provided accessible information on the changes to the system that are taking place, and the implications of these changes on them. Practitioners are trusted by service users and can be a useful source of information. However, they may have a self- interest in promoting some services over others. User led organisations may be better placed to provide independent advice, although there is little hard evaluation evidence around this.

The change to personal budgets can have significant implications for providers. Some providers may be exposed if they are offering services at a higher price or inefficiently, although political decisions can be taken to protect some provision. The experience of the Netherlands is that efficient providers can respond to fill gaps left by less efficient service providers exiting the market.

## Personal budgets

Personal budgets have been used as a tool to retain more people in their own homes. This can be beneficial for the individual and reduce costs. Most benefits appear to occur where individuals are supported and given good information to make appropriate choices.

Personal budgets may be a useful tool in Ireland’s plan to decongrege people living in large settings, especially in reducing the numbers entering such facilities and possibly also opening up options for people who might want to move out

That said, there is little evidence that offering personal budgets encourages people to leave a care home if they are already there. This may reflect the nature of those in care homes in the case studies countries and the political decision taken in the Netherlands that care home residents would not be removed if they no longer met eligibility criteria. A similar decision allowing people to remain in suitable residential accommodation may be appropriate in Ireland.

## Quality in service

Offering service users flexibility in how they spend their budget should be encouraged, so long as a link can be made meeting need and to achieving the outcomes agreed in the care plan. The extent to which different countries seek to control how the budget is spent and how accountable people are, varies widely.

There are often some restrictions around spending, either in terms of what it can be spent on or, more tightly, the providers with which it can be spent. This gives rise to questions about the suitability of provision available in the local market. With the move from centralised and block contracts commissioning into personal budget, authorities need to develop a local market of services, offering a choice from which services can be purchased. The market will not develop on its own simply by users’ demand, especially as pressure on budgets can mean the market is not attractive to new entrants. Therefore, funders of the system need to undertake market development if service users are to be offered real choice.

* New providers can be attracted by framework contracts which set fairly low barriers to entry (in effect a relatively deregulated market), and this appears not to pose a major risk to quality, so far there is little evidence that these new providers have lowered quality but this must be monitored.
* 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.

Service users will require access to reliable, up to date information about services available. This can be done through directories or online. It is likely that better support and information will lead service users to make more appropriate choices.

## Governance

Payments appear to be made regularly to service users, say monthly or even three or six month depending on the amount and a risk assessment of the service user. Fraudulent use of personal budget was generally thought to be low, although we only found one set of figures to corroborate this. Therefore, while it should be a component of any payment system, controls should be proportionate and complex systems of regulation that require high level of reporting may not be necessary.

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. The extent of control overlaps with the issue of market regulation as discussed above. A more deregulated market might call for more frequent checks on how money is spent.

There are well documented risks around using personal budget to pay family members, particularly around concerns that the state would be paying for services that otherwise would be provided at no cost (as part of looking after a family member) and that the introduction of a financial element could lead to a potentially unhealthily dependent relationship. There is little actual evidence of this, perhaps because payments to family members have been excluded in many areas. That said, and given practice elsewhere it would seem reasonable for Ireland to adopt a policy on not allowing personal funding to be paid to immediate family members.

At the same time, it will be important to be clear what level of family support is expected. This is likely to vary from case to case depending on personal circumstances. The extent to which this level of support is actually delivered should also form part of the review process.

Online systems of payments appear to offer a range of benefits: they provide a ready audit trail and reduce the burden on users to keep records and therefore may encourage take up of direct payment options. However, the additional benefits which arise and potential value for money are unclear in the literature and would therefore require further research. A national system is likely to provide economies of scale over disparate local systems.

## Areas for further research

As we began this chapter by saying, although there is little literature around case-mix and some literature around personal budgets, very little of it is comparative or evaluates different delivery models. Rather it tends to focus on the overall impact in terms of service user outcomes or cost implications. Therefore, there remains many issues which are uncertain and would benefit from further research, including:

* The differences that arise in the value of budgets and later outcomes dependent on whether the assessment is carried out independently or by a practitioner familiar with the service user
* What differences arise in terms of the final budget value and outcomes when the budget is agreed before or after the development of a care plan
* How the data gathered through assessments and reviews could be used to track progress in outcomes (or monitor a decline in conditions) and this could be used to monitor audit service provision
* How service users can best be informed about the range and quality of provision available, and whether such information does induce a change in service provider, and in time lead to better outcomes
* What the relative costs are of the various options considered above – for example a standalone independent agency against additional tasks for care workers to conduct assessments, or a relatively unregulated market with the implicit savings around monitoring and assessment of providers against a highly proscriptive model.

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# Annex B: Literature search terms

## Social Care Online:

(Subject Terms: Direct Payments including this term only OR Subject Terms: personal budgets including this term only OR Subject Terms: personal health budgets including this term only OR Subject Terms: personalisation including this term only OR Abstract: cash for care OR Abstract: individual budgets) AND (Subject Terms: risk including this term only OR Subject Terms: risk assessment including this term only OR Subject Terms: risk management including this term only OR Subject Terms: financial abuse including this term only)

### Google:

* Financial risks of Direct Payments to local authority
* Inappropriate OR risk "Direct Payments"
* Risk management~ individual budgets~
* Case-mix funding cash budgets
* Cash budgets "Casemix funding" social care
* Governance cash budgets
* Governance "cash for care" "Direct Payments" "self-directed support" "personalised payments"
* Direct budgets in education

"Casemix funding" allocation systems "systematic review"

Governance "cash for care" systematic review

### Google Scholar:

* Financial risks abuse Direct Payments reviews
* "Risk management"~ "individual budgets"~ "personalisation"~
* Casemix funding cash budgets
* Casemix funding allocation systems personal budgets
* "Casemix funding" individual budgetsindividual budgets
* Governance cash budgets
* Allintitle: "casemix funding"
* "Cash for care" governance
* In-kind care payments governance
* Allintitle: "Diagnosis Related Groups"

### ASSIA:

(su(risk assessment) OR su(risk) OR su(risk management) OR su(financial abuse) OR su(assessment of risk)) AND (su(direct payment\*) OR su(personal budget\*) OR su(personal health budget\*) OR su(personalisation) OR su(cash for care) OR su(individual budget\*))

(ab("direct payment\*") OR ab("personal budget\*") OR ab("personal health budget\*") OR ab(personalisation) OR ab("cash for care") OR ab("individual budget\*")) AND (ab("risk assessment") OR ab(risk) OR ab("risk management") OR ab("financial abuse") OR ab("assessment of risk"))

### MEDLINE:

(su(direct payment\*) OR su(personal budget\*) OR su(budgeting personal) OR su(personal health budget) OR su(personalisation) OR su(cash for care) OR su(individual budgets)) AND (su(risk) OR su(risk assessment) OR su(risk and risk management) OR su(risk management) OR su(financial abuse))

ProQuest 8 Databases; ASSIA, BNI, MEDLINE, PILOTS, ProQuest Hospital Collection, ProQuest Sociology collection, PsycARTICLES and PsycINFO

 (ab("direct payment\*") OR ab("personal budget\*") OR ab("personal health budget\*") OR ab(personalisation) OR ab("cash for care") OR ab("individual budget\*")) AND ab(risk) OR ab("risk assessment") OR ab("risk management") OR ab("financial abuse") OR ab("assessment of risk") limit article

 ((ab("direct payment\*") OR ab("personal budget\*") OR ab("personal health budget\*") OR ab(personalisation) OR ab("cash for care") OR ab("individual budget\*") OR ab("cash budgets\*")) AND (ab(risk) OR ab("risk assessment") OR ab("risk management") OR ab("financial abuse") OR ab("assessment of risk") OR ab(fraud))) AND (ab("social care") OR ab("social services") OR ab("social science"))

Ovid Journals; Journals@Ovid Full Text, Your Journals@Ovid,

AMED (Allied and Complementary Medicine), Embase, HMIC Health Management Information Consortium, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present, Ovid MEDLINE(R) Daily Update Ovid OLDMEDLINE(R) 1946 to 1965, Social Work Abstracts, NASW Clinical Register 14th Edition, Social Policy and Practice 201510

(Case?mix adj3 fund\*).ti. or (case?mix adj3 fund\*).ab. Limited by 2011-2016

##

## Gaps Search

### MEDLINE

1. “Cash transfers”.ti,ab.
2. "Cash for care".ti,ab.
3. "Cash payment$".ti,ab.
4. ((Individual or direct or personal) adj3 budget$).ti,ab.
5. "Voucher schemes".ti,ab.
6. "Activity Based Costing".ti,ab.
7. "Diagnosis Related Groups".ti,ab.
8. "Casemix".ti,ab.
9. or/1-7
10. ((Self-directed or consumer-directed) adj care)
11. Personalisation.ti,ab.
12. Person-centred.ti,ab.
13. Risk$.ti,ab.
14. Assessment$.ti,ab.
15. Management.ti,ab.
16. Abuse.ti,ab.
17. Responsibility.ti,ab.
18. Appeals.ti,ab.
19. Systems.ti,ab.
20. Procedures.ti,ab.
21. Frameworks.ti,ab.
22. Resource allocation.ti,ab.
23. Mechanisms.ti,ab.
24. Effectiveness.ti,ab.
25. Allocation.ti,ab.
26. or/10-25
27. Health.ti,ab.
28. Hospital$.ti,ab.
29. Social care.ti,ab.
30. Social service$.ti,ab.
31. Community care.ti,ab.
32. Disability.ti,ab.
33. Education.ti,ab.
34. (Care services or care systems or care provision).ti,ab.
35. Consumer.ti,ab.
36. Commissioning.ti,ab.
37. or/27-36
38. Review$.ti,ab.
39. Randomised control$ trail$.ti,ab.
40. Randomized control$ trial$.ti,ab.
41. Qualitative.ti,ab.
42. Quantitative.ti,ab.
43. Survey.ti,ab.
44. View$.ti,ab.
45. Cross sectional.ti,ab.
46. Stud$.ti,ab.
47. Meta-analysis.ti,ab.
48. or/38-47
49. 9 and 26 and 37
50. 48 and 49
51. Historical Article/
52. Editorial/
53. Comment/
54. Letter/
55. News/
56. Animals/
57. Humans/
58. 56 not (56 and 57)
59. or/51-55,58
60. 50 not 59
61. Limit 60 to English language
62. Limit 61 to YEAR="2000 -Current"

Results = 383

# Annex C: List of research questions

## General questions – all applications of resource allocation system

### Individual Assessments

1. What triggers an initial assessment and is there an eligibility threshold?
2. Who conducts assessments – a State agency, a service provider, an independent person, other? (specify)
3. What is the involvement of the individual, their family, professionals, their key worker/service provider in the assessment? What role for self-evaluations?
4. What grade of staff/ qualifications, and what training required to conduct assessments?
5. How often are re-assessments done for a disability population?
6. What factors would trigger more frequent re-assessments?
7. What form does the output of the assessment take for example score, monetary amount, hours of service required, statement of need, care plan, other (please specify).
8. Is there a guarantee that the individual will receive the supports (including monetary supports) identified by the assessment? If not, is there a systematic process for determining the quantum of supports (including monetary supports) provided?
9. Is the allocation of resources to individuals a top-down or bottom-up process (sometimes also referred to as prospective and retrospective models):
* Top-down (prospective) approach: the individual’s allocation is determined prior to the development of their person-centred plan, using a standardised assessment to set a general budget level;
* Bottom-up (retrospective) approach: the individual’s allocation is determined through discussion and negotiation during the person-centred planning process.

### Data

1. How is assessment data held, and who is responsible for the data?
2. Is assessment data used at the level of the individual for purposes such as individualised service planning or measurement of outcomes? Specify
3. Is the assessment data used at regional or national level for other purposes such as service planning, audit of performance or measurement of outcomes? Specify

### Transparency of resource allocation

1. How transparent is the link between assessment and subsequent service funding to those participating in the assessment?
2. Do service providers know what a person with a particular profile entering their service is likely to get under the resource allocation formula?

### Integrity of assessment process

1. What systems are in place to deter assessment of needs as higher than they are to attract more funding (gaming the system, or ‘upcoding’)?
2. Who audits assessments and subsequent service funding??
3. How are audits done (for example, checks on individuals and on statistical patterns)?

### Scope of Resource Allocation System

1. What items are in and what are out for example personal care needs (activities of daily living), personal support needs (instrumental activities of daily living), personal assistance (assistance to support social inclusion and engage in training), clinical, nursing or therapy supports, transport, assistive technology, aids and appliances, other (please specify)?
2. How are overheads dealt with?

### Systems for non-standard need

1. How are exceptions dealt with, for example cases where the support needs are exceptionally high or not adequately provided for under the standard formula?
2. How are very short-term needs for support dealt with?
3. How are intermittent and unpredictable support needs addressed?
4. How are progressive needs addressed?
5. What proportion of budget is reserved to provide for unforeseen or exceptional needs?

## National or Regional Resource Allocation Model

### Administration

1. Please give examples of national, regional or local authorities which have implemented a resource allocation model linked to individual assessments of need
2. Does the national resource allocation process, including the assessment of individual need, have a statutory basis?
3. Is one standard assessment tool used for all disability assessments within a defined administrative area (national, regional or local authority) or is a mix of tools used? Is the same tool used for children and adults; for people with all types of disability; by all service providers; for both day and residential supports (people living in the community and people in traditional residential care settings)?
4. Is a single national casemix system and costing formula used (that is, the formula used to associate costs with assessed needs), and how has it been derived?
5. What is the system to adjust the national costing formula over time to reflect factors such as inflation? What cost drivers are taken into account in determining the adjustment?
6. Is the national resource allocation model, casemix system and costing formula reviewed periodically to see whether they are fit for purpose?
7. How often is the casemix system reviewed or the basic formula recalibrated? Is recalibration triggered by factors other than inflation, such as reductions or increases in the national budget for disability services, increasing or decreasing demand, the inclusion / exclusion of services and supports being funded, other?
8. Is there a process of stakeholder engagement or consultation in the administration and periodic adjustment of the national resource allocation model?
9. What proportion of individual assessments result in budgetary amounts being offered (direct cash payments) to those assessed?
10. Are there other methods of assigning choice and control over supports to individual service users, such as vouchers, statements / certificates of need which are transferable across service providers, or other methods (please specify).

### Appeals

1. What is the system for service providers to appeal budget allocations based on case-mix?
2. What is the system for individuals to appeal service offers/individualised funding/personal budgets based on resource allocation assessment?

### Transition from block funding to case-mix for service providers

1. Over what period were case-mix systems introduced as the basis for funding service providers? What worked well?
2. How was the old model phased out and the new model phased in?
3. Any transition funding given to soften the blow for losers under the new allocation system?
4. Any specific challenges, difficulties or resistance?
5. Were ‘dummy runs’ done to show providers what they could expect to get in a full roll-out?

### Quality in services

1. How is the quality of services accounted for?
2. Is performance of different service providers compared for example league tables re outcomes achieved?
3. What is relationship between quality control as a funder re outcomes achieved, and inspection/audit/regulation?
4. Are there any bonuses associated with achievement of quality, or fines for quality failures?
5. How is it possible to ensure that service providers do not direct resources towards measured needs and away from unmeasured ones?

### Individualised budgets/ Personal budgets

1. What services are monetised?

### Transitioning to personal budgets

1. How is that phased in (for example geographically, by age group, new applicants, at points of transition or service review etc.)?
2. If individuals transition out of collective services (for example day services), how is their share of the budget separated out, and what happens if costs are now spread over fewer people?

### Governance

1. How often and how is the money paid?
2. Who receives the personal budget if the person lacks capacity to manage their own affairs?
3. What safeguards are in place against financial abuse, particularly of those with diminished capacity, and to ensure that cash budgets for individuals are actually spent on their support needs?
4. What checks are in place to ensure funding achieves intended outcomes?
5. What is the optimal balance between flexibility of use and accountability?
6. How often are checks made on the individual budget holder’s account, and in what percentage of cases? What form does this check take?

# Annex D: Literature review

## Introduction

This review is organised under the following headings:

* Resource allocation models
* Use of the personal budget
* Governance
* Transition to a new system
* Take up.

## Resource allocation models

The literature review found variation in the resource allocation models used at national and regional levels. It found that some resource allocation models cover whole countries, for example, Da Roit and Le Bihan (2010) found that Austria and Germany each had a national resource allocation model for cash-for-care schemes. France also used a national resource allocation model as identified by Le Bihan and Martin (2010).[[9]](#footnote-9) However there was no consistency and each country appeared to have a different resource allocation model, for example the Austrian system was based on a grid with seven levels of need, the French system had six levels of need, whereas the German resource allocation model had three levels (Da Roit and Le Bihan, 2010).[[10]](#footnote-10) Resource allocation models at the national level were the minority and there was more evidence of regional or local authorities having autonomy over the resource allocation model used. For example, Gadsby (2013) found that within the American Cash for Counselling pilot there was variation by state:[[11]](#footnote-11)

* Arkansas AM used a set price per hour
* Florida based their calculation on the individual’s previous service usage, or a care plan if previous usage was not stable
* New Jersey resource allocation model used the value of the care plan, minus tern percent that was set aside for support services

Italy was another example where the resource allocation model used was decided locally (Longo et al, 2015).[[12]](#footnote-12)

Although there was evidence that a variety of resource allocation models were used, there was little information in the literature about the scope of each resource allocation model. For example it appears as though the resource allocation model used across France is for any individual with a Long Term Health Condition (LTC) (Le Bihan and Martin, 2010).[[13]](#footnote-13) However further research would be required to established whether this is actually the case.

The literature suggests that the resource allocation models use a variety of costing formula. Gadsby (2013) identified that in England two approaches to costing formula are prevalent. The first is goal based, where a plan is costed based on the individuals’ goals and objectives. How the objectives are met is considered second as is the cost of the services. The second approach is menu based, which uses services that are already identified and then costed. A local example from Lincolnshire, England, shows that they used a points based system for individual budgets. The points were accrued by an individual depending on their answers to multiple choice questions. The points were then translated to a monetary value (Rowlett and Deighton, 2009).[[14]](#footnote-14) The approach is aligned to the goal based system identified by Gadsby (2013).

The six tiered grid system used in France leads to a monetary value and is assessed on an individual’s level of dependency (Le Bihan and Martin, 2010).[[15]](#footnote-15) The examples mentioned previously from America also evidence that the hours of care needed and service usage can be used in costing formula (Gadsby, 2013).[[16]](#footnote-16) There was evidence that the hours of care needed were also used in Lincolnshire, England however this metric was used for direct payment calculations rather than individualised budgets (Rowlett and Deighton, 2009).[[17]](#footnote-17)

There was evidence of a statutory basis for Direct Payments and individual budgets in the literature, for example, the Health and Social Care Act 2001 in England and the Community Care and Health (Scotland) Act 2002 in Scotland (Ridell et al, 2006).[[18]](#footnote-18) The statutory basis of resource allocation models, including the assessment of individual need however was unclear in the literature.

There was evidence that changes to costing formula may be necessary to respond to changing demographics. For example, the elderly population in France is forecast to grow and as a result the money spent on LTC policies could increase from one percent to two-two and a half percent of GDP over a 20-25 year period (Le Bihan and Martin, 2010).[[19]](#footnote-19) However, there was no evidence in the literature to suggest that any countries had made changes or had a regular review process.

Todd (2009) identifies that ‘it is important to collect accurate data on the usage of the resource allocation system, review this data and learn from this process in order to improve the resource allocation systems and other components of self-directed support’.[[20]](#footnote-20) However, the literature does not provide any evidence that countries are reviewing their resource allocation model, casemix system or costing formula periodically. So it is not possible to conclude from the information available what triggers a review, the review process, or what stakeholders are involved in a review.

## Resourcing

Gadsby (2013) suggests that some countries have a fixed budget, ‘often on a scale determined by an individual’s assessed level of care dependency’ which is ‘usually calculated in terms of hours of care required.’[[21]](#footnote-21) He uses the USA as an example of a country with a more flexible budget and regional variation in method: in Arkansas, the figure is calculated as a set price per house, written in the care plan, whereas in Florida, the figure is calculated based on previous service usage or the care plan where this information is not reliable (ibid).[[22]](#footnote-22) Both states adjust the budgets to keep expected programme costs at a comparable level to former agency-based services (ibid).[[23]](#footnote-23) However in New Jersey, it is the value of the care plan, minus ten percent (set-aside for support services, not defined) which is used to calculate the personal budget figure (ibid).[[24]](#footnote-24)

Beer et al (2013) raised concerns that devolution in England may result in a ‘postcode lottery’ of National Health Service care, with some people able to access personal budgets with a much greater degree of freedom and flexibility over how to spend it, compared with someone in another area (Beer et al, 2013).[[25]](#footnote-25) This is supported by the finding that the value of personal budgets in England and Scotland have been higher than those in Northern Ireland or Wales, and within England itself, rates were highest in London and the South East and lowest in the South West (Ridell et al, 2006).[[26]](#footnote-26) In the United Kingdom ‘responsibility for the implementation of direct payments within purchasing authorities var[ies] greatly,’ and in the USA ‘a high degree of policy decentralisation has led to considerable federal-level variation in American social-care provision’ (ibid).[[27]](#footnote-27)[[28]](#footnote-28)

In the Netherlands, personal budget values are 25% lower than the cost of the care equivalent, but 10 – 15 percent of budget holders still manage to repay some of their annual allocation each year (Gadsby, 2013).[[29]](#footnote-29) However there is no evidence to show whether budget holders receive a comparable level of care for a lower price, or whether the money is simply being diverted elsewhere (ibid).[[30]](#footnote-30) In contrast, Medicaid personal care costs are higher under the pilot Cash and Counselling scheme because users are receiving more of the care package that they were / are entitled to receive (ibid).[[31]](#footnote-31) According to the National Health Service, standardised assessment schemes avoid discriminating against particular groups of people, for example older people with family carers, ensuring transparent allocation of resources (National Health Service Confederation, 2009).[[32]](#footnote-32) However SQW found that ‘the issue of dropout [from an individual budget pilot scheme] appeared to relate to the issue of transparency,’ that is, if they were not told in advance how the value of their allocation might change (Thom and Prabhakar, 2010).[[33]](#footnote-33)

## Appeals

The literature review found no information on appeals. Manthorpe et al (2011) state that ‘there is little yet on the systems of appeals, complaints, and discretion that might underpin the procedural justice of this’ (Gadsby, 2013).[[34]](#footnote-34)

## Undertaking the assessment

The literature review has uncovered information on how eligibility for personal budgets varies by country, and on who and how assessments should be conducted. Manthorpe et al (2011) suggest that social workers or care managers conducting the assessment is problematic because they may fill in the forms back at the office rather than with the client. The form may then reflect the social worker or the service’s priorities rather than the client’s needs (ibid).[[35]](#footnote-35) In a later paper, Manthorpe et al (2015) recommended that social workers should carry out the assessment, but by implication from concerns raised in their earlier work, this should be done alongside the service user.[[36]](#footnote-36) Similarly, Beer et al (2013) recommend that an experienced clinician and care worker conduct the assessment based on client needs.[[37]](#footnote-37) Wilberforce et al (2014) expect assessment to be client-led and outcomes-focussed, however self-assessment can be problematic if users over- or under-estimate their needs (particularly older people) or if carers are overlooked (Manthorpe et al, 2015).[[38]](#footnote-38)[[39]](#footnote-39) This again make the case for assessment to involve both the social worker and the service user.

In the USA in the pilot Cash and Counselling scheme, it is trained, independent state staff who conduct assessments and Gadsby (2013) suggests their role is more to act as an advocate for the user than as an ‘objective assessor of need.’[[40]](#footnote-40)[[41]](#footnote-41) In the Netherlands too, an independent organisation (CIZ – the Dutch Care Assessment Agency) is responsible for carrying out assessments, according with the national assessment tool (Da Roit and Le Bihan, 2010).[[42]](#footnote-42) In Germany, potential applicants apply to the agency responsible for the payments. If the agency accepts their application, they are invited to a budget conference and their needs are assessed then (Junne and Huber, 2014).[[43]](#footnote-43)

The literature review has recovered limited information on the level of qualifications / training required for conducting assessments. Assessors on the Cash and Counselling scheme in the USA are specifically trained independent state staff (Gadsby, 2013).[[44]](#footnote-44) There is no mention of specific training in France or the Netherlands, but there are national assessment scales which assessors are expected to follow (Le Bihan and Martin, 2010; Da Roit and Le Bihan, 2010).[[45]](#footnote-45)[[46]](#footnote-46) The literature review found limited information on the form of the assessment output.

## Use of the personal budget

In 2006, Ridell et al reported that ‘almost a third of direct payment recipients with physical impairments in England received funding equivalent to more than 31 hours of support per week, and three quarters received intensive care packages.’[[47]](#footnote-47) Additionally a majority of users focused their budget on support for personal care (ibid).[[48]](#footnote-48)

A ‘care package’ is an ‘indication of hours per week [and] describes which function it delivers, such as support, personal care, nursing, daytime activities and treatments’ (Grit and Zuiderent-Jerak, 2015).[[49]](#footnote-49) In theory the budget can be used for alternative therapies and one-off items (for example a computer or Wii Fit); Manthorpe (2009) even reports that someone with very high support needs can put Direct Payments towards the cost of buying a house (Gadsby, 2013).[[50]](#footnote-50)[[51]](#footnote-51) However, in practice, countries place varying levels of restriction on how, where and what the money can be spent on. During the Direct Payments pilot in the UK there was confusion over what non-traditional services or items the money could be purchased (ibid).[[52]](#footnote-52) Manthorpe et al (2011) suggest that users had more freedom to buy non-traditional goods and services under the pilot than they have now.[[53]](#footnote-53)

According to Gadsby (2013), Finland restricts users’ choices by providing a list of approved suppliers and France similarly provides an approved list of care packages (Manthorpe et al, 2011).[[54]](#footnote-54) The scope of personal budgets in England, Australia, the Netherlands and the USA seems broad at first, however in reality, they all have conditions and processes in place which require money to be used towards ‘specifically identified outcomes or lists of approved services or goods’ (ibid).[[55]](#footnote-55) Sweden, Germany and France are less restrictive over how the money is spent.[[56]](#footnote-56) In Germany, users are left to decide how to spend the budget on a day-to-day basis and are checked retrospectively by a local agency (Junne and Huber, 2014).[[57]](#footnote-57) Gadsby (2013) outlines the permitted use of personal budgets in the following eight countries:

* England: budgets may be used to purchase mainstream services, employ personal assistants and to pay for leisure activities. Sometimes they can be used for one-off purchases. They do not need to be used to pay for GP services or emergency health services.
* Belgium: budgets must be used to employ a personal assistant or pay for services from a [specified] choice of providers. At least 95% of the budget must be spent on salaries.
* France: the budget must be used to fund specific care packages or to employ a personal assistant.
* Germany: budgets can be used to pay for: transport, nursing, assistance in the workplace, leisure activities, therapy costs, support equipment, and services provided by health or care insurance which are needed regularly and on a supplementary basis. Budgets cannot be used to pay for GP costs.
* The Netherlands: budgets can be used to pay for personal care, nursing care, support services (for example day-time activities) and short-stay / respite care for holidays / weekends. Budgets cannot be used for alternative treatments, medical treatments, or treatment by allied health professionals.
* Austria: budgets are mainly used to compensate family members for informal care.
* US: what budgets can be spent on varies by state; each state controls the permitted range of services and equipment. Generally, all states allow the budget to be spent on personal assistants and care-related goods and services. Some states allow users to purchase skilled nursing and long-term rehabilitative therapies. Other states allow budgets to be spent on clinical recovery services for people with serious mental health conditions.
* Canada: budgets can be used to purchase disability-related supports. They cannot be used towards the cost of medical supplies or equipment, home renovations, electronic equipment, leisure or recreation purposes, or personal / family costs.[[58]](#footnote-58)

In France, the direct payment made to older people allows them to purchase their own care from a relative (not a spouse) if they wish, although it tends to be used to purchase care from not-for-profit organisations, rather than individuals (Rummery, 2008).[[59]](#footnote-59) A similar system is in operation in the Netherlands, although the direct payment tends to be used to employ personal carers, including migrant workers in the ‘grey market’ (ibid).[[60]](#footnote-60)

## Role of the family

The role that the family / close friends play or are expected to play in caring for vulnerable relatives – who may be personal budget holders - is complex and varies by country. Not all countries allow direct family members (particularly spouses) to be paid as carers. There is a ‘general factoring in of a level of unpaid family support’ into personal budget allocations in the UK, USA and (since 2012) in the Netherlands, where there is a reliance on informal family care (more for childcare than adult care) (Beer et al, 2013; Rummery, 2008).[[61]](#footnote-61)[[62]](#footnote-62)[[63]](#footnote-63) In Italy, Greece and Spain, family care is the only option, whereas Denmark, Finland, France, and Sweden have moderate-to-highly developed formal care systems (Rummery, 2008).[[64]](#footnote-64)[[65]](#footnote-65) Carr (2011) reported that in the UK, ‘families [are] expected to provide a high level of [care] support on an informal basis and unpaid basis but their contribution [is] not recognised.’[[66]](#footnote-66) This accords with Manthorpe et al’s (2011) caution that using family carers to compensate for a lack of services ‘can institutionalise a system of low-paid care and make family members dependent on the service user for whom they are caring.’[[67]](#footnote-67)

C.22 Family members acting as paid carers can have advantages for both users and the carer themselves. Particularly in communities where it is hard to hire suitable carers (for example black and minority ethnic communities and isolated rural communities) paying family members as personal carers can help to solve a recruitment problem (Ridell et al, 2006).[[68]](#footnote-68) Furthermore, people may be happier to be cared for by someone close to them, or happier knowing that their relatives are receiving compensation for doing so. For unpaid family carers, payment may allow them some freedom from the obligations of full-time care, if they know they can afford to draw on social work cover when they need a break (Carr, 2011).[[69]](#footnote-69)

In 2008, Rummery reported that the number of unpaid and family carers was falling, due to changing relations and expectations within families and communities.[[70]](#footnote-70) It may be that more family members could afford to provide this level of care if they were financially compensated. However, introducing a paid element into family care can lead to dependency relationships, intergenerationally (for example, disabled adult child-parent, or daughter-in-law/daughter-parent) and intragenerationally (for example, between spouses) (ibid).[[71]](#footnote-71) Rummery (2008), citing Ungerson (2004) suggests that paying family members ‘has the result of commodifying relationships and expectations, with the possibility of exploitation and abuse of vulnerable parties on both sides’ (ibid, Ungerson, 2004; Mitchell et al, 2012).[[72]](#footnote-72)[[73]](#footnote-73)[[74]](#footnote-74) Benjamin (2001) also reports professionals’ feelings that ‘familial ties complicate what should be an employer-employee relationship between workers’ (Benjamin, 2001).[[75]](#footnote-75)

Furthermore, Manthorpe et al (2011) have suggested that an emphasis on family support discriminates against personal budget holders who do not have a family network to draw on.[[76]](#footnote-76)

Family are expected to carry out two functions: direct support (care) and advisory support (budget administration). The position of family care is set out by country below:

### Netherlands

#### Direct support:

In the Netherlands, families are relied upon to provide informal care for disabled or sick relatives (Rummery, 2008).[[77]](#footnote-77) Initially, personal budget assessments did not account for how many hours of unpaid care a family could provide; an oversight which they later rectified as now, a level of unpaid family care is accounted for before a user’s personal budget allowance is calculated. Payments to carers are ‘routed through recognised care agencies’ and come from the Social Insurance Bank (Beer et al, 2013; Rummery, 2008; Ungerson, 2004).[[78]](#footnote-78)[[79]](#footnote-79)[[80]](#footnote-80) Van den Berg and Schut[[81]](#footnote-81) warned of the growing burden on the social care system in 2003; as informal care replaced paid informal care via personal budget allowances, families who did not originally qualify for financial assistance became eligible for support (Beer et al, 2013).[[82]](#footnote-82) Parents of disabled children were amongst the highest group of new claimants (ibid).[[83]](#footnote-83)

#### Advice:

In 2007, Ramakers et al found that only 35 percent of budget holders in the Netherlands administered their budgets themselves, while the others either enlisted family help, or relied on someone else to administer the budget for them (Ramakers et al, 2007, in Gadsby, 2013: 10, table 2).[[84]](#footnote-84)

### United States of America

#### Direct support:

When the Cash and Counselling programme was introduced in the US, officials were concerned that they would be financing family care which was previously been provided free of charge. As a result, personal budget assessments calculate the level of support a user requires over and above the care which can be reasonably expected from the family (Carr, 2011).[[85]](#footnote-85) If they choose to do so, users can spend their budget on personal care from whomever they want (ibid).[[86]](#footnote-86) Federal Medicaid rules allow personal budget expenditure on ‘legally responsible’ family members (spouses and parents), but the extent to which particular family members are allowed to be paid (grandparents, etc.) varies by state (Benjamin, 2001).[[87]](#footnote-87) An early evidence review of the Cash-for-Care scheme (2001) found very little evidence of fraud or abuse by either family or non-family carers (ibid).[[88]](#footnote-88)

#### Advice:

Federal Medicaid regulations allow personal budgets to be paid to ‘legally responsible’ family members (spouses or parents) in cases where the recipient is not able to administer the budget themselves (Benjamin, 2001).[[89]](#footnote-89)

### Italy

#### Direct support:

In Italy the family are relied upon to provide informal care for their relatives.

#### Advice:

There is a reluctance at the state level to provide a formal response to the rising demand for long-term care in the country (Rummery, 2008).[[90]](#footnote-90)

### Austria

#### Direct support:

Austria operates a system of state-facilitated private care (ibid).[[91]](#footnote-91) A non-means tested benefit is paid directly to disabled and older people, which can be used to pay family members for direct care support (as well as other private carers, particularly migrant workers) (Oesterle, 2001; Rummery, 2008).[[92]](#footnote-92)[[93]](#footnote-93)

#### Advice:

In Austria there is very little state support for personal budget holders, leaving them reliant on the family to either advise them on how to manage their budget, or to manage the budget on their behalf (Gadsby, 2013).[[94]](#footnote-94)

### France

#### Direct support:

France has a ‘familialist’ welfare system, which means there is a strong national ethos of family care (Rummery, 2008).[[95]](#footnote-95) Intergenerational solidarity is a legal obligation in France, causing public sector support to become secondary to family care (Le Bihan and Martin, 2010).[[96]](#footnote-96) However, family members can be reimbursed for caring for a relative; their payment is routed through recognised care agencies in order to formalise the system and protect the carer (Rummery, 2008).[[97]](#footnote-97) In 2010, Le Bihan and Martin reported that 75 percent of the dependent elderly are cared for by their families and 50 percent of these carers are spouses (2010).[[98]](#footnote-98) Eighty percent of carers in France at the same time were aged 50 – 70 (ibid).[[99]](#footnote-99)

#### Advice:

As in Austria, state support is very limited and direct payment holders are left to rely on family members to advise them on how to administer their budget, or manage it for them (Gadsby, 2013).[[100]](#footnote-100)

### Germany

#### Direct support:

Germany operates a system of state-facilitated private care (Rummery, 2008).[[101]](#footnote-101)

#### Advice:

As in Austria and France, state support for personal budget holders is very limited and users are reliant on family members to advise and help them to administer their budget (Gadsby, 2013).[[102]](#footnote-102)

### England

#### Direct support:

In England, the family is relied upon to provide formal care (Rummery, 2015).[[103]](#footnote-103) The number of hours of unpaid care which a family can provide is accounted for in personal health budget assessments (Beer et al, 2013).[[104]](#footnote-104) With regards to social care, unpaid family carers can request an assessment by their local authority to see whether they are ‘eligible’ for assistance in providing that support, that is, it is assumed that the family will care for their relative even in the case of not receiving state assistance to do so.[[105]](#footnote-105)

#### Advice:

Research in 2008 found that families and carers could also benefit from the individual budgets scheme if they were provided with the right advice and support themselves (Carr, 2011, citing Glendinning et al, 2008).[[106]](#footnote-106) Lincolnshire County Council is a widely cited example of best practice with regards to the transition to personal budgets (Rowlett and Deighton, 2009).[[107]](#footnote-107) Reported in 2009, personal budget holders in Lincolnshire could spend £250 on independent legal advice (ibid).[[108]](#footnote-108) They and their family members could work through example trust deeds with an adviser, which were then checked by Lincolnshire County Council’s legal team before Direct Payments were made (ibid)[[109]](#footnote-109).

## Systems for non-standard needs

The literature review did not identify any information on systems for non-standard needs, other than Kodner’s (2003) mention that some of the overall budget was put aside for flexible use.[[110]](#footnote-110) Mitchell et al (2012) report that ‘one specific gap identified in recent research is the need for evidence on how to support people in identifying and managing risks when their symptoms and abilities fluctuate’ (Manthorpe, 2008).[[111]](#footnote-111)[[112]](#footnote-112) This is particularly relevant for people with mental health needs but also for those with other fluctuating conditions (ibid)[[113]](#footnote-113).

## Governance

The literature review found that regulation of personal budgets varies by country, with Germany, the Netherlands, France and Sweden subject to ‘strong accountability controls’, while Italy and Austria have largely unregulated systems (Carr, 2011; Rummery, 2008).[[114]](#footnote-114)[[115]](#footnote-115) Key differences are whether users are allowed to purchase personal care from family members (specifically spouses) and whether an unregulated ‘grey market’ of low-paid carers exists, although in practice the differences are even more complex. For example, in Italy, where regulation and checks on users are low, there exists an unregulated labour market of low-paid carers (ibid).[[116]](#footnote-116) In the Netherlands, personal budget users are allowed to employ their relatives as carers, who receive their wages through the Social Insurance Bank, but spouses / partners may only be employed if the user provides them with an employment contract (Ungerson, 2004; Arksey and Kemp, 2008).[[117]](#footnote-117)[[118]](#footnote-118) However, while Dutch regulation makes it impossible to employ carers through the unregulated market, only one in twenty people employ a full-time personal assistant, while the majority choose to employ multiple carers, avoiding paying social insurance contributions and bypassing regulation (Rummery, 2008; Timonen et al, 2006; Arksey and Kemp, 2008).[[119]](#footnote-119)[[120]](#footnote-120)[[121]](#footnote-121) Regulation can be seen simultaneously as an invasion of personal caring relationships (and the complex reciprocities involved in these), but also as a protection for both vulnerable users and low-paid personal assistants, who are vulnerable to exploitation (and are mainly women) (Rummery, 2008).[[122]](#footnote-122)

Countries have varied requirements of budget holders: Austrian and Finnish programmes ‘require little input from providers / commissioners and expect little in the way of financial reporting’, while France, Belgium, Sweden and Australia offer more support but are designed in such a way that limits user autonomy (Gadsby, 2013).[[123]](#footnote-123) In contrast, systems in England, the US, Netherlands, Canada and Germany have complex programmes which require a high level of provider input but are designed to enable a high degree of user autonomy (in theory) (ibid).[[124]](#footnote-124) These latter systems then tend to be the most highly regulated. For example, in England, auditing is high and users are held to serious account if they are found to have spent their budget ‘incorrectly’.

The literature review found the most information on auditing and regulation of the English personal budget system. In 2010, the Audit Commission found that ‘experience from Direct Payments suggests that levels of abuse are low’, however they also recommended that social workers are trained in fraud mitigation (Beer et al, 2013).[[125]](#footnote-125) Beer et al (2013) recommend that councils promote whistleblowing arrangements amongst staff, service providers and members of the public, to report suspected fraud and abuse of the personal budget system, suggesting a system which is suspicious of its user group. However they also clarify that ‘misuse does not always equate to fraud’ and sometimes users are unsure of the complex implicit and explicit Local Authority expectations of how their budget should or should not be spent (ibid; Junne and Huber, 2014).[[126]](#footnote-126)[[127]](#footnote-127)[[128]](#footnote-128)

Councils have the right – and have – taken individuals to court (or settled out of court) to reclaim money which they believed to have been spent inappropriately. Beer et al (2013) states that it is important to make users aware of this possibility from the outset.[[129]](#footnote-129) Junne and Huber (2014) found that funders they interviewed had taken legal action in 5 out of 155 cases for reasons of fraud or non-disclosed use of Direct Payments (in Beer et al, 2013).[[130]](#footnote-130) In one case, a woman who had used her budget on horse-riding lessons (as a form of alternative therapy) was investigated by the authorities, who had not explicitly prohibited expenditure on this activity but did not expect budget funds to be spent in such a way (ibid).[[131]](#footnote-131) While this is one specific example, it highlights the complexity of managing the balance between risk (of the budget being spent incorrectly and of harm to the user) and regulation: regulation should be proportionate to risk (Glasby, 2011).[[132]](#footnote-132) Some councils publish guidelines on how personal budgets should be spent, but Manthorpe et al (2011) suggest users may find this patronising and restrictive (Manthorpe et al, 2011).[[133]](#footnote-133)

Both English and American systems encourage or oblige users to develop a support plan to manage their budgets. In the Cash and Counselling case, this is a prerequisite for an authority passing the budget, which may only be spent on ‘health and disability related [social care] needs [and] not to cover general expenses or luxury items’, that is, it can only be spent on home support or personal care (Carr, 2011).[[134]](#footnote-134) Reporting on a case of good practice, Rowlett et al (2009) explains that Lincolnshire County Council require users to keep all paperwork on expenditure, which is subject to regular audit, ‘alongside the normal care assessment and review process’ (Rowlett and Deighton, 2009).[[135]](#footnote-135) In their research with adult safeguarding practitioners in 13 English Local Authorities (locations unspecified), Manthorpe et al (2009) cite one reported example of a financial audit occurring every 13 weeks ‘to help the person make sure they’re not getting behind in payments and tax payments.’[[136]](#footnote-136) The practitioner thought it ‘a little bit heavy but we still want to have it in [as] we are looking for a system to highlight overspends’ (ibid).[[137]](#footnote-137)

In England, Germany, the Netherlands and the US, Gadsby (2013) finds that ‘the wellbeing of the care recipient is reviewed periodically, and, if care is deemed insufficient, the cash allowance is withdrawn in favour of services provided by a home care agency.’[[138]](#footnote-138) This suggests that appropriate use of financial resources is not the authorities’ only concern. However, Gadsby also reports that in practice, reviews of personal health budgets in England ‘varied in formality and timing’ and over one-third of interviewees had not had any kind of review (face-to-face, telephone or postal) (ibid).[[139]](#footnote-139) This left users feeling ‘disappointed, abandoned and a bit adrift’ as they were unsure how much money they had left, feared overspending, and worried about who knew what was going on and was taking responsibility for them and their budget (ibid).[[140]](#footnote-140)

There are three main ways that a user can access a personal budget: a direct payment to their bank account; an account held by the Council or a third party who ‘manages’ it on their behalf (for example to pay for services); or a mix of both (Carr, 2011; Needham, 2013; Manthorpe et al, 2009).[[141]](#footnote-141)[[142]](#footnote-142)[[143]](#footnote-143) 40 percent of local councils in England also provide pre-paid chip-and-pin debit cards, which allow users to avoid setting up a bank account for their Direct Payments and to easily pay for non-traditional services or carers (Beer et al, 2013).[[144]](#footnote-144) Users can keep track of their expenditure online or via monthly payments, but councils / local authorities can block the card if the user is abusing the system (ibid).[[145]](#footnote-145) Kent was the first county to introduce pre-paid cards. Beer et al (2013) further suggest that a voucher system – similar to vouchers for other National Health Service services (for example dental care) could be used for personal health budgets although this would require extensive planning and organisation, incorporating non-traditional providers. In the future, Beer et al (2013) suggest that we can expect to see lots more single payment or short-term personal budget allocations.[[146]](#footnote-146) At the moment, the necessity of setting up a new bank account for a personal budget is off-putting for service users; however, it is possible that recipients of short-term payments may be able to receive money directly into their personal accounts, in exchange for providing a full breakdown of their bank statement (ibid).[[147]](#footnote-147) Whilst this may deter users, it is already common practice in housing benefit applications and Beer et al suggest this may be a real possibility for future personal budget holders (ibid).[[148]](#footnote-148)

The literature review did not find information on how often money is paid to personal budget holders.

## Balance between flexibility and accountability

While personal budgets are designed to offer users the freedom and flexibility to choose their support package, Rowlett and Deighton (2009) asserts that in practice, the degree of flexibility afforded to UK users varies by local authority but ‘many place quite narrowly defined parameters around how the money can and cannot be spent.’[[149]](#footnote-149) SCIE (2010) advocate a ‘lighter approach to monitoring [which] needs to be balanced with the requirements of legitimate audit trails and accountability for public money.’[[150]](#footnote-150) The National Health Service Confederation (2009) also advocates ‘greater capacity in managing budgets flexibly within care management.’[[151]](#footnote-151) Manthorpe et al (2011) suggest that a focus on outcomes, rather than on ‘fitting users into existing services’ would help to improve the creativity and flexibility with which personal budgets can be employed.[[152]](#footnote-152)

Junne and Huber (2014) outline the perils of non-compliance with the implicit and explicit expectations for personal budget expenditure.[[153]](#footnote-153) As mentioned previously, ‘non-appropriate’ expenditure could result in termination of a user’s personal budget, or a court order to force them to repay the wrongly-spent money (ibid)[[154]](#footnote-154). In response, there are some reports of care assistants – such as this interviewee (a care assistant and legal representative for users who need to negotiate with local agencies) from Germany - negotiating authority requirements in order to seek out a little more freedom for service users:

“In the target agreement I always try to organise something in between a SMART [Specific, Measurable, Attainable, Relevant, Time-bound] and a general target, because, eventually, the requirement of a SMART target takes any freedom away… I always argue that the work on the detail is something that does not belong to the target agreement but to the operationalisation… I want to have some room to manoeuvre. I want to be able to react to eventualities and sometimes it is not yet 100 per cent clear, how I will do something” (ibid).[[155]](#footnote-155)

Junne and Huber further report that negotiations of this kind are ‘coping strategies’ for users whose theoretical freedom to choose their own support, is in reality, constrained (ibid).[[156]](#footnote-156)

One way in which users can retain control is by choosing their own personal assistant, who may or may not have been subject to a CRB (Criminal Records Bureau check, now called Disclosure and Barring Service) check (Glasby, 2011).[[157]](#footnote-157) While this raises safeguarding issues for the service user in particular (as a vulnerable person), this is an example of allowing a user the right to manage their own risks (with support from key workers). Another way groups of users have exercised control in England is to pool their resources to pay for a personal assistant, rent a room in a community centre for a party or meeting, or pay for a coach to go on a day trip (Needham, 2013).[[158]](#footnote-158) While at the time of writing there were no clear guidelines or limitations on pooling budgets, Needham (ibid) suggested that staff may think it is ‘not allowed’ and prevent it from happening.[[159]](#footnote-159) In Norway, parents have also exercised choice over the use of personal budget allocations for their disabled children, by choosing to employ a nanny or pay for child care over staying at home with their child, as expected (Bungum and Kvande, 2013).[[160]](#footnote-160)

Beer et al (2013) believe it is only a matter of time before personal budget users follow-up a session paid for with a personal budget allowance, with a session paid for out of their personal funds.[[161]](#footnote-161) In theory, this is not against National Health Service rules, if the additional session was voluntarily requested, occurred on private premises and was paid for separately (ibid).[[162]](#footnote-162) While a user should not need to pay for additional care out of their own pocket, this is likely to happen because there is inevitably a subjective difference between a user’s assessed level of need and the user’s perception of their own needs (ibid).[[163]](#footnote-163)

## Quality of services

The literature raises more questions about the impact of personalisation on the quality of services, than it provides answers for. Throughout the literature there are two key themes: regulation and quality measures.

Individual budgets have led to some services not being regulated. For example, Benjamin (2001) found that traditionally care would be given by a care worker employed by a licensed and certified home care agency. The home care agency would be required to take action if there were any concerns about the care given by one of their employees which was a mechanism for quality assurance. However support that was consumer directed, for example purchased with an individual budget, may remove this quality assurance mechanism if care is not purchased from a home care agency (Benjamin, 2001).[[164]](#footnote-164) Similar to Benjamin (2001), Arksey and Kemp (2008) found a lack of regulation of services when purchased with cash-for-care payments. They however identify that there are a variety of views as to whether more regulation is needed:

* Formal quality assurance mechanisms are not needed as recipients can and will change their assistant if they are not happy with the care provided (Tilly et al., (2000))
* Regulation is not needed as disabled people are capable of assessing the quality of services, regulation could be perceived to be paternalistic and patronising to disabled people (Doty et al., 1996)

Arksey and Kemp (2008) however found that there was also concern about the lack of regulation as some vulnerable service users may be at risk.

How quality is defined is another common theme in the literature. As the evidence on regulations suggests those receiving care are commonly thought to be best placed to judge the quality of the care they receive. For example, in the Netherlands there is no official system to supervise the quality of care as the underlying assumption is that ‘budget holders will make up their own minds about quality’ (Gadsby, 2013). How consumers judge the quality of the services they receive is not fully understood based on the evidence in the literature. Benjamin (2001) found that those in receipt of care are likely to consider a number of variables when judging the quality of their care including what is: appropriate; adequate; comfortable; and secure. Professional standards were thought to only have limited impact on service users’ assessment of quality (Benjamin, 2001).[[165]](#footnote-165) Both Benjamin (2001) and National Health Service Confed (2009) suggest that quality such be defined by service users and measures of quality should be informed by their values and reported outcomes.

A case study in California compared the service outcomes of users of self-directed support with those of users of agency-based services. There was no difference in safety and unmet need service outcomes but the self-directed support were more positive about service satisfaction and quality of life (Benjamin, 2001).[[166]](#footnote-166)

## Transition to a new system

The literature identified a number of challenges during the transition period for service providers. There were four specific challenges mentioned in the literature concerning the transition phase, these were: staff resistance; supply of staff; finance; and legalities. The challenges are summarised in Table D-1 and expanded in the text that follows.

Table D-1: Challenges during transition for service providers

| Challenges | Why |
| --- | --- |
| Staff resistance to Direct Payments[[167]](#footnote-167) [[168]](#footnote-168) | Perception that Direct Payments may reduce job security and may reduce working conditions, for example, carers employed directly by users may not receive employment related benefits |
| Difficulties regarding the supply of personal assistants (regional differences meant that this was also an enabler in some areas)[[169]](#footnote-169) [[170]](#footnote-170) | There is a general lack of capacity in some regions and the job may become less attractive if, for example, carers employed directly by users did receive employment related benefits  |
| Perception that care is more expensive per unit when purchased individually (lack of economies of scale)[[171]](#footnote-171)  | Leading to financial insecurity which may in turn lead to the closure of some services  |
| Legal considerations – legalities unclear and confusion regarding changing rules[[172]](#footnote-172)  | Acted as a barrier to take up and led to concern amongst service providers particularly around risk and safeguarding of the individual |

Source: Various, see footnotes

To ensure that the transition to a Direct Payments system is successful, services and front line staff must be involved from the outset (Manthorpe et al, 2011).[[173]](#footnote-173) The relationship between the service and its users, the range of services on offer and the allocation of resources must also be considered and managed (Manthorpe et al, 2009).[[174]](#footnote-174) Consumer-directed services can be seen as a threat to social worker jobs and consequently trade unions can also be resistant (Arksey and Kemp, 2008).[[175]](#footnote-175) Social service agencies which have a limited commitment to user involvement or are conservative in their approach to independent living are less likely to engage with and actively promote cash-for-care schemes (ibid).[[176]](#footnote-176) For example, because there is resistance to personal budgets at various levels in Scotland, the social care market was relatively under-developed (ibid).[[177]](#footnote-177) As a result, direct payment users were a minority and the impact of personal budgets on service users has been minimal (this is also the case in Northern Ireland) (Ridell et al, 2006).[[178]](#footnote-178)

Ridell et al (2006) comment that ‘expanded Direct Payments usage is unsustainable without well-resourced and knowledgeable support services to direct users’ (ibid).[[179]](#footnote-179) There is concern that demand for services may grow, as ‘new’ physically disabled users ‘come out of the woodwork’ (as their needs could now be met in a way which traditional services could not) and support services may become overburdened and lack the resources to provide the same level of support to users (as was the case in the Netherlands and less problematically, in Belgium) (Gadsby, 2013).[[180]](#footnote-180) In the Netherlands, eligibility for personal budgets has been scaled back since 2012 as costs were spiralling out of control (ibid).[[181]](#footnote-181) This happened because eligibility was flexible and ‘largely based on trust’ (Beer et al, 2013) increasing the pool of potential applicants; the level of (free) available family care was not initially taken into account in assessments, and; disabled users whose needs had not been met by traditional support services took the opportunity to claim additional services which were more appropriate to their needs (ibid; Gadsby, 2013).[[182]](#footnote-182)[[183]](#footnote-183)[[184]](#footnote-184)

This is partly to do with a greater potential volume of users, and partly with shrinking finance to providers, as services lose block (council) contracts they must rely solely on the income generated from personal budget payments.

In 2013, Gadsby reported that 90% of funding for community services and 2/3 of the funding for mental health services was provided under block contracts.[[185]](#footnote-185) Change is a slow process and councils may find it hard to extract themselves from legal contracts leaving them liable to cover the double cost of existing contracts and personal budget payments (Manthorpe et al, 2015; Manthorpe et al, 2011).[[186]](#footnote-186)[[187]](#footnote-187) Rowlett and Deighton (2009) and Beer et al (2013) suggest that money could be taken away from National Health Service-provided services in England if users choose to spend their budget on non-traditional services instead, which could destabilise the National Health Service services and lead to closures, particularly in rural areas (Rowlett and Deighton, 2009; Manthorpe et al, 2011).[[188]](#footnote-188)[[189]](#footnote-189)

In Germany, cash payments are seen as a cost-saving measure and are typically half the value of formal services (Gadsby, 2013).[[190]](#footnote-190) If service users cannot afford to pay for as wide a range of services as they received through their traditional package, then this is likely to affect them, as well as the providers. Providers are concerned that staff might lose their jobs or employment and sickness benefits (Manthorpe et al, 2009).[[191]](#footnote-191)

However, there has been some positive response by providers in Lincolnshire who see it as a chance to re-haul services and boost effectiveness (Rowlett and Deighton, 2009).[[192]](#footnote-192) This includes services focusing on one type of client (rather than providing for a wide range of needs) in order to reduce overheads and staffing costs (Grit and Zuiderent-Jerak, 2015).[[193]](#footnote-193) Providers must respond to the fact that clients have greater choice and ‘exit options’ if they are not happy with the service they are receiving (ibid).[[194]](#footnote-194) Gadsby (2013) reports on a review by Propper et al (2006) which found that ‘whilst there is neither strong theoretical nor empirical support for competition, there are cases where competition has improved outcomes.’[[195]](#footnote-195)[[196]](#footnote-196) For example, in Sweden studies have suggested that the new market for personal assistances is more price-competitive than the public sector, reducing costs overall.[[197]](#footnote-197)

While it takes time for individual budgets to embed in the local service system there has been a growth in both the number of voluntary organisations providing services and of in-house support schemes.[[198]](#footnote-198)[[199]](#footnote-199) However there is concern that this is compromising user-led services and raising questions about ‘the sustainability of the link between the independent living movement and direct payment users.’[[200]](#footnote-200) This is significant given that Carr (2011) found that ‘the systems which appear to be most appreciated by recipients are those which ‘safeguard their determination’, are linked to a clear local support strategy and are routed through organisations of disabled people.’[[201]](#footnote-201)

Furthermore, the market for skilled personal assistants has not responded as positively, raising ‘concern about the extent to which local authorities are shifting quickly enough into their new role as market shaper rather than commissioner of services’ (Needham, 2013).[[202]](#footnote-202) As Arksey and Kemp (2008) argue, ‘in order to exercise choice there needs to be a social care market generating a supply of care workers or service providers.’[[203]](#footnote-203) Junne and Huber (2014) raised concerns that Direct Payments ‘deskill and fragment those providing services and service users hired their own care assistants and tender to favour the cheapest and least qualified, preventing the development of a skilled and well-paid workforce.’[[204]](#footnote-204) In Italy and Austria in particular there are large unregulated ‘grey’[[205]](#footnote-205) workforces’ of migrant personal assistants and there are safeguarding questions around both the user and the migrant worker (Gadsby, 2013).[[206]](#footnote-206)There is a further question regarding the power-relations between service providers and users. While personal budgets are supposed to empower the user, Grit and Zuiderent-Jerak (2015) report that supplier’s positions are strengthened as clients are ‘required to fit their demands to the core package they receive [which the supplier offers].’ This makes it easier for providers to say no to demanding or challenging clients.

There is a further question regarding the power-relations between service providers and users. While personal budgets are supposed to empower the user, Grit and Zuiderent-Jerak (2015) report that supplier’s positions are strengthened as clients are ‘required to fit their demands to the core package they receive [which the supplier offers].’[[207]](#footnote-207) This makes it easier for providers to say no to demanding or challenging clients.

The literature review found that the future of day-care centres in particular, is uncertain. Day-care centres are ‘not funded by groups of individuals pooling their funds but are accessible shared spaces which are collectively provided’ (Needham, 2013).[[208]](#footnote-208) Day-care workers (Unison members, across England) report centres closing, changing their structure or changing their eligibility criteria (ibid).[[209]](#footnote-209) For example, some centres are restricting access to self-funders, care home residents, and people who do not regularly attend (ibid).[[210]](#footnote-210) Some centres have started charging users, either to cover the cost of refreshments, transport, or a set amount to cover the cost of the day (ibid).[[211]](#footnote-211) Needham (2013) reports that ‘day services are now called ‘day opportunities’ and a budget of £30 provided. Effectively, this rations the service and means that someone can only have one day at a day-care centre funded by social services. Service users with personal budgets are expected to have funds to cover these costs’ (ibid).[[212]](#footnote-212) Where users are signposted to alternatives, these tend to be basic (ibid).[[213]](#footnote-213) This affects both users of traditional care packages and direct payment users.

C.57 Grit and Zuiderent-Jerak (2015) report on providers’ requests for a ‘workable form of accountability.’[[214]](#footnote-214) While collective accountability at location level is possible, accounting for groups of clients, it is not feasible for them to account for every client individually (ibid).[[215]](#footnote-215) In practice, providers hope not for ‘complete transparency of care package spending per client’ but instead just for ‘some information on duration [of service support], including collective or group hours’ (ibid).[[216]](#footnote-216) However, they also suggest that ‘the improved transparency of results at local level is driving providers to adjust supply better’ (ibid).[[217]](#footnote-217) ‘Improved transparency of results’ means that total service hours delivered is recorded more clearly, so the economic efficiency of different locations can be compared and poorly performing areas can be targeted (ibid).[[218]](#footnote-218)

Benjamin (2001) raises concerns about the system becoming too professionalised: ‘with the push to include training for consumers as they start self-direction, along with training for workers and family members and the pressure to introduce satisfactory quality assurance measures, there is a risk that consumer-directed services will become so layered with service providers, case managers, support teams and quality assessors, that they will be transformed into another professional mode of care.’[[219]](#footnote-219)

Transitional funding was made available in Scotland and Manthorpe et al (2011) identified that it was ‘a helpful spur for innovation’. Similarly, in England the Department for Health awarded local authorities that were pilot or demonstration sites extra funding (£520 million during 2008 -2011) to assist with ‘their ‘transformation’ to personalisation’ (Needham (2013)). However further research would be required to understand how the transitional funding worked in practice and what impact, if any, it had on service providers.

There was evidence in the literature that the social care market was changing and becoming more innovative in response to personalisation. This was, as summarised by Rose (2009, in Newman, 2009), because new solutions were necessary to support a more personalised approach: ‘many of the social care products available are the traditional products (for example residential care) and there is little point in controlling your own budget if all you can buy is what you would have got under the old system.’[[220]](#footnote-220) Ridell et al (2006) found that the move towards personalisation was also leading to new user-led support groups and community-based organisations. These organisations raised awareness of opportunities and were thought to be a positive new source of support.

However not all new services and providers were thought to be positive. Manthorpe et al (2011) identified that a grey or casual market for personal assistants in particular might develop in Scotland. This may be due to economies of scale being diminished by the lack of block funding and commissioning. The grey market would be a symptom of self-direct support payments being insufficient to fund high quality services.[[221]](#footnote-221)

Although the introduction had led to new entrants to the market, some existing providers were slower to innovate and change their practice and respond to personalisation (Gadsby (2013). Gadsby (2013) identified that it would take services providers time to change their attitudes and ways of working.

## Risk management and mitigation

Personal budgets can be perceived as ‘risky’ for multiple parties: personal budget holders (shifting responsibility from service providers onto service users, liquidity issues, safeguarding, violating ‘appropriate’ use of budget risk of abuse by carers; lack of support); families and carers (potentially subject to the ‘grey market’ of informal, low-paid, unprotected and potentially illegal, work) and; support services (budgets being spent incorrectly / fraud lack of central professional control, potential closure of traditional services due to lack of demand and funds) (Junne and Huber, 2014; Manthorpe et al, 2009; ibid).[[222]](#footnote-222)[[223]](#footnote-223)[[224]](#footnote-224)

Person-centred planning of personal budgets is key (SCIE, 2010).[[225]](#footnote-225) Risk can be managed most effectively by engaging with the user: assessors and / or social workers should spend a considerable period of time with the person, in order to understand how they want to live their lives, what risks are subsequently most pertinent and need to be addressed and negotiated, and what level of safeguarding is appropriate for that person (ibid, 2011; Glasby, 2011).[[226]](#footnote-226)[[227]](#footnote-227) It is very hard to manage risk without proper context (ibid).[[228]](#footnote-228) Manthorpe (2007) found that social workers are increasingly prioritising risk assessment tools over subjective judgements, which leaves fewer opportunities for social workers and users to develop understanding relationships (Manthorpe, 2007, in Mitchell et al, 2012; Mitchell et al, 2012).[[229]](#footnote-229)[[230]](#footnote-230) Rather, ‘risk management strategies and safeguarding processes should be developed with the person using the services as part of the personal budget and support plan’ and risk should be shared between the two parties (SCIE, 2010, Glasby, 2011).[[231]](#footnote-231)[[232]](#footnote-232) Furthermore, there is a tendency for frontline practitioners to make preconceived judgements of the ‘riskiness’ of particular groups of people, such as those with mental health problems (SCIE, 2010).[[233]](#footnote-233)

Mitchell et al (2012) report ‘widespread uncertainty and a lack of evidence’ on how best for support workers to encourage positive risk-taking, suggesting that practitioners need more guidance and training on risk enablement and management. SCIE (2010) and Glasby (2011) raise 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’ (Mitchell et al, 2012; SCIE, 2010; Glasby, 2011; SCIE, 2010).[[234]](#footnote-234)[[235]](#footnote-235)[[236]](#footnote-236)[[237]](#footnote-237) Risk can be managed in multiple ways: 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 (SCIE, 2010).[[238]](#footnote-238) It is important that someone remains responsible for risk monitoring and risk assessment once the support plan and personal budget are in place (Mitchell et al, 2012).[[239]](#footnote-239)

Risk enablement panels should only ever be used in ‘exceptional circumstances’ and are not authorised to provide additional support to manage risks (SCIE, 2010).[[240]](#footnote-240) However, SCIE (2010) believe that they offer ‘a way of helping with challenging or complex decisions that may occur as part of the support plan validation process.’[[241]](#footnote-241) The aim of a risk enablement panel is to reach a decision which is made collectively, transparently, and encourages positive risk-taking (ibid).[[242]](#footnote-242) SCIE recommend that the panel would include: the individual and / or their advocate; personal carers (if appropriate); independent chairperson; Local Authority safeguarding lead; relevant multidisciplinary staff and; relevant specialists (ibid).[[243]](#footnote-243) Hartlepool’s In Control pilot study used their panel as ‘a learning set for cultural change’ and a platform for challenging risk-averse practice (ibid).[[244]](#footnote-244)

## Safeguarding

There is an acknowledged need to align personalisation and safeguarding more closely (Mitchell et al, 2012; Carr, 2011; SCIE, 2010).[[245]](#footnote-245)[[246]](#footnote-246)[[247]](#footnote-247) Self-direction empowers service users by connecting them directly to support services, in turn promoting prevention and early intervention because users know who to go to for support (ibid; Gadsby, 2013).[[248]](#footnote-248)[[249]](#footnote-249) However, it is a balancing act: 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 vulnerable adults are appropriately protected from harm or abuse (SCIE, 2010).[[250]](#footnote-250) Personal budget practitioners and adult safeguarding staff must work together ‘to ensure that procedures are aligned and person-centred (ibid).’[[251]](#footnote-251) Carr (2011) writes that ‘an indication of a supportive system is one which clearly incorporates self-directed support with safeguarding policy and practice, with abuse detection and risk enablement training for both staff and people using personalised services’ (Carr, 2011).[[252]](#footnote-252) Manthorpe (2009) suggests training personal budget users to be aware of adult protection services, how to identify abuse and who to contact in the instance of abuse occurring.[[253]](#footnote-253)

As part of the USA Cash and Counselling programme, the ‘counselling’ element involves regular checks (by telephone or in person) for abuse or neglect of users with ‘subtle behavioural changes or other cues during telephone contact… prompt[ing] a home visit by a counsellor’ (Gadsby, 2013; SCIE, 2010).[[254]](#footnote-254)[[255]](#footnote-255) One of practitioners’ key safeguarding concerns regards users directly employing personal assistants: while this is the most beneficial option for service users, a lack of legislation enforcing DBS checks for directly-employed carers puts users at risk of abuse (Spandler, 2004; Manthorpe et al, 2011).[[256]](#footnote-256)[[257]](#footnote-257) However, people’s safeguarding needs vary and there is a need to avoid a ‘one-size-fits-all’ approach to regulation: according to Glasby (2011), we ‘need to find ways of being clear when certain safeguards are necessary and when these are simply not needed and only get in the way.’[[258]](#footnote-258)

## Staff, training and culture

Strong local leadership is a necessity if central government policy on personal budgets is to be adopted successfully (Manthorpe et al, 2015).[[259]](#footnote-259) SCIE wrote in 2010 that ‘a transformation of local authority culture and systems [organisation] is needed to put people, rather than processes, first.’[[260]](#footnote-260) The drive for change must come from the top if it is to infiltrate down and change daily practice, with practitioners ‘shar[ing] their aspirations for independent living’ with service users (Carr, 2011).[[261]](#footnote-261) Training and supporting frontline staff and first line managers is crucial, in order to ‘manage change, improve knowledge and assessment practice, promote equality and diversity awareness, and to challenge perceptions about risk and capacity for certain groups’ (the elderly, those with mental health conditions or those with severe learning difficulties) (ibid).[[262]](#footnote-262) Rather than focusing on process auditing and personal budget administration, frontline workers should embody a system which is ‘culturally competent, person-centred and relationship-based’ and staff should be confident and well-informed (ibid).[[263]](#footnote-263)

However, training is not enough on its own; staff must be properly supported to be a part of the transformation, be encouraged to communicate their experiences and funding should be ring-fenced, if real systematic change is to be achieved. Staff training should not be a ‘bolt-on’ to an otherwise unchanged system (ibid).[[264]](#footnote-264) Ridell et al (2006) found that training for social workers and support staff varied by local authority and was more effective in areas with a ‘designated officer or champion’ of personal budgets.[[265]](#footnote-265) Fraud awareness training for social workers has also been suggested (ibid).[[266]](#footnote-266)

In 2013, Gadsby noted that attempting to change the attitudes and practices of care managers and staff had proved ‘challenging’, and ‘a great deal of change [was] required, in both professionals’ and patients’ attitudes, understandings and expectations, before the key principles behind personal health budgets [could] be fully attained.’[[267]](#footnote-267) Reviewing the situation in 2015, Manthorpe et al commented that ‘individual senior managers’ personal attitudes and cross-sector expertise are still regarded as crucial in promoting personal budgets (Larsen et al, 2013).[[268]](#footnote-268) There is little evidence about how to sustain the changes demanded by [self-directed support]’ but commentators have noted the importance of user or peer support as well as professional or managerial leadership or promotion of change (Dawson, 2009; Manthorpe et al, 2015)’.[[269]](#footnote-269)[[270]](#footnote-270) Training for everyone, particularly social workers, is seen as valuable, but there is little evidence of what skills need to be developed among the workforce (ibid, citing Manthorpe et al, 2009).[[271]](#footnote-271)

The literature also finds that training for service users, family members and carers, and independent advisors / counsellors, is highly beneficial (SCIE, 2010; Manthorpe et al, 2009).[[272]](#footnote-272)[[273]](#footnote-273) As previously mentioned, there is debate over how best to negotiate the balancing act of ‘allowing’ personal budget holders the freedom to choose their own personal assistant (who may or may not have professional caring qualifications), with the duty of care to protect vulnerable adults, particularly in the United Kingdom (Gadsby, 2013; Graham, 2015).[[274]](#footnote-274)[[275]](#footnote-275)

## Take up

The general trend across countries has been a slow initial take up of personal budgets, followed by an increase over time as people become more aware of and confident taking up the opportunities a personal budget could bring (National Health Service Confederation, 2009).[[276]](#footnote-276) Carr (2011) reports that ‘evidence from piloting and early adoption shows that some people will use the flexibilities to design very different services, while others (most notably older people) value the ability to adjust more conventional packages to deliver a service more responsive to their own needs’ (Carr, 2011).[[277]](#footnote-277) However, it is important that users understand personal budgets not as ‘a solution to a range of problems’, but rather as a means of ‘improving personal control’ (National Health Service Confederation).[[278]](#footnote-278)

According to Carr (2011), the implementation and take up of personal budgets was initially ‘patchy and inequitable.’[[279]](#footnote-279) In England, the US, Australia and Sweden, there was ‘considerable local variation in the ways programmes were implemented’, which affected take up (Gadsby, 2013).[[280]](#footnote-280) Gadsby (2013) reports that the evaluation of personal budgets for social care in England brought ‘implementation difficulties, with users, carers and service providers subject to ‘new stresses… as they adapted to new procedures’ (Glendinning et al, 2008; Gadsby, 2013).[[281]](#footnote-281)[[282]](#footnote-282) Consequentially, personal budget programmes took a while to embed in the local service system (Carr, 2011).[[283]](#footnote-283)

Slow take up in England, Belgium, Germany and Finland, was partly due to the implementation challenges outlined above, but also due to a lack of demand from service users (ibid).[[284]](#footnote-284) This could have been for several reasons, including: a perception that the administrative burden of a personal budget was too great; users (or carers) not wanting such a high level of responsibility for their services; or concerns that personal assistants were either hard to hire, or put stress on family relationships (if the user did not want to hire a relative) (Manthorpe et al, 2011).[[285]](#footnote-285) Furthermore, the suitability of personal budgets for some user groups, such as dementia patients and the elderly, has been called into question (Gadsby, 2013).[[286]](#footnote-286)

Carr (2011) asserts that ‘as part of exercising the choice over their care and support, some older people may prefer to keep existing service arrangements’ (Carr, 2011).[[287]](#footnote-287) However, in Denmark, even amongst the elderly, ‘attitudes towards the idea of changing providers [has] shifted over time’ (ibid).[[288]](#footnote-288) In Belgium, low take up was deliberate, as the number of new budget holders was strictly controlled in order to prevent spiralling costs (Gadsby, 2013).[[289]](#footnote-289) In the UK, former Under-Secretary of State for Care Services, Paul Burstow MP, suggested that take-up was low because social workers wanted to ‘maintain control over how care funding should be spent’, causing outcry from social workers, who reported that it was users - particularly the elderly and those without someone to manage the money for them - who did not want to take up a personal budget (Woolham et al, 2015).[[290]](#footnote-290)

In 2001, O’Brien argued that ‘the success of individualised funding initiatives should be measured by the rate of transition from consumer to agent; in other words, how far they generate active and creative negotiators or ‘agents’ rather than simply reproduce passive consumers’ (O’Brien, 2001).[[291]](#footnote-291) In 2011, Carr found that ‘personal budget holders [in England] [were] beginning to use them to increase participation and activity in their communities, to access universal services, education, training and employment, and to promote independent living’ (Carr, 2011).[[292]](#footnote-292) However, this is not a universal transition, while 37 percent of people in the English social care pilot used their individual budgets for leisure activities, and 22percent used it for short holidays or other ‘one-off’ purchases, 59percent of users still used some or all of the money to purchase traditional services (Gadsby, 2013).[[293]](#footnote-293) Gadsby (2013) reports that this was ‘sometimes because they felt the amount of the budget was inadequate to cover and support over and above their personal care’ (Glendinning et al, 2008).[[294]](#footnote-294) In the case of families looking after disabled children, it has been suggested that carers were simply not aware of the scope of available services or how much they might cost (Thom and Prabhabkar, 2010).[[295]](#footnote-295) However, this highlights the need for widely available and accessible information, advice and support for service users thinking of transitioning to a personal budget; including an explanation of how the administrative processes work (Manthorpe et al, 2011; National Health Service Confederation, 2009).[[296]](#footnote-296)[[297]](#footnote-297)

In the USA Cash and Counselling pilot, 80 to 90% of all users (excluding disabled children and young adults with developmental disabilities) used all or part of their budgets to pay for a personal carer, of which 58 to 78% hired family members (Gadsby, 2013).[[298]](#footnote-298) However, research has found difficulty getting personal assistants in the UK, particularly in affluent areas and commuter belts where there is already a lot of domestic support work, or in areas where large-scale employers (such as a call centre) have recently set up (Ridell et al, 2006).[[299]](#footnote-299) Writing in 2006, Ridell et al reported that half of Welsh local authorities reported difficulties in personal assistant recruitment.[[300]](#footnote-300) Furthermore, recruitment in rural areas can be hard because service users are reluctant to hire someone from within their small community who is likely to know (of) them, which means recruiting someone from outside who has to travel in to help them (Ungerson, 2004; Arksey and Kemp, 2008).[[301]](#footnote-301)[[302]](#footnote-302)

How best to overcome these issues and how to spend a personal budget more generally, can be eased with the assistance of counsellors (in the US), service support staff, or support brokers. In the USA Cash and Counselling programme, all users were required to undergo training on how to set up a support plan and how to recruit and train workers (Gadsby, 2013).[[303]](#footnote-303) Furthermore, 93percent of users accessed the ‘fiscal intermediary service’ to help with book-keeping (ibid).[[304]](#footnote-304) In Arkansas, it was compulsory for users to develop a spending plan with a counsellor within 45 days of enrolling (ibid).[[305]](#footnote-305) All age groups accessed counselling services at a similar level, and across all ages and states, 85-95percent of users found the services helpful (Brown et al, 2007).[[306]](#footnote-306) In the UK, Gadsby (2013) has found that users tended to look for free support brokerage from professionals they already know, rather than pay for professional support brokerage (Gadsby, 2013).[[307]](#footnote-307) However, in the Netherlands there have been problems with care mediation officers taking too much control over both managing user’s budgets and providing their care (ibid).[[308]](#footnote-308) In some cases, this led to incidences of fraud (ibid).[[309]](#footnote-309)

# Annex E: List of consultees

1. Jill Manthorpe, Professor of Social Work at King’s College London - England
2. Brant Fries, President of interRAI - USA
3. Catherine Needham, Reader on Public Policy and Public Management at the University of Birmingham – England and Scotland
4. Beth Hall, Lead at Convention of Scottish Local Authorities - Scotland
5. Boris Stam, Dutch Institute of Health and Welfare and member of interRAI – The Netherlands
6. Tdjalke de Jong, Dutch Institute of Health and Welfare – The Netherlands
7. Dee Fraser, Development Manager, Commissioning and Procurement at CCPS - Scotland
8. Shona McGregor, Development Manager, Self-directed Support at Social Work Scotland - Scotland
9. Jack Blaik, Independent Living Fund Scotland - Scotland
10. Jacob Gindin, Head of the interRAI committee for international development - Israel
11. Nick Rowlett, Director at Linriss Limited - England
12. Sarah Carr, independent adult social care and mental health consultant; formerly Lead: Personalisation Work Programme at SCIE - England
13. Tim Gollins, Lead for Self-directed Support and Personal Budgets at ‘Think Local Act Personal’ - England
1. Case Mix: a term which is used in the UK health planning circles, refers to the sum total of the diagnoses present in a population and the high and low resource therapies that are required to manage them are considered as a single unit for the purpose of resource analysis and allocation planning (Segen J. C. 1992) [↑](#footnote-ref-1)
2. Van den Berg, B and Schut F.T., 2003. ‘The end of free informal care?’ Economische Statistische Berichten. 88,4413; 420–2 [↑](#footnote-ref-2)
3. Waters J, and Hatton C, (2014) Third National Personal Budget Survey, Experiences of personal budget holders and carers across adult social care and health. Available online http://www.thinklocalactpersonal.org.uk/\_assets/Resources/SDS/POET\_social\_care\_FINAL\_Oct\_24.pdf [↑](#footnote-ref-3)
4. The Dutch Healthcare Authority (NZa) is an autonomous administrative authority, falling under the Dutch Ministry of Health, Welfare and Sport (VWS). https://www.nza.nl/organisatie/sitewide/english/ [↑](#footnote-ref-4)
5. Thom, G and Prabhakar, M (2010) Individual budgets for families with disabled children, Final evaluation report: recommendations and implications [↑](#footnote-ref-5)
6. Commissioners in local public services are responsible for identifying population needs and work with a range of providers to develop and procure service specifications, usually from preferred providers. [↑](#footnote-ref-6)
7. In 2011 the Department for Education set up 20 trials with 31 local authorities to test the proposal in the SEN&D Green Paper with the aim to improve the support available to children and young people with special educational needs and disabilities. <https://www.gov.uk/government/collections/send-pathfinders> [↑](#footnote-ref-7)
8. SQW has done an evaluation of the costs of developing care plans for children and young people in four areas looking at old versus new delivery systems. SQW came to a view that new system was more expensive, but that wasn’t consistent across all four areas and the evaluations was done at an early stage of transition to the new system. [↑](#footnote-ref-8)
9. Le Bihan, B and Martin, C (2010) Reforming long-term care policy in France: private-public complementarities, Social Policy and Administration, 44(4), pp.392 - 410 [↑](#footnote-ref-9)
10. Da Roit, B and Le Bihan, B (2010) Similar and yet so different: cash-for-care in six European countries’ long-term care policies, The Milbank Quarterly, 88(3), pp.286-309 [↑](#footnote-ref-10)
11. Gadsby, E (2013) Personal Budgets and Health: a review of the evidence, PRUComm [↑](#footnote-ref-11)
12. Longo, F, Notarnicola, E and Tasselli, F (2015) A framework to assess welfare mix and service provision models in health care and social welfare: case studies of two prominent Italian regions, BMC Health Services Research, pp.1-12 [↑](#footnote-ref-12)
13. Le Bihan, B and Martin, C (2010) Reforming long-term care policy in France: private-public complementarities, Social Policy and Administration, 44(4), pp.392 - 410 [↑](#footnote-ref-13)
14. Rowlett, N and Deighton, S (2009) Simplifying direct payments: How Lincolnshire County Council utilised risk management to deliver genuine improvement, Journal of Care Services Management, 3(2) pp.131-143 [↑](#footnote-ref-14)
15. Le Bihan, B and Martin, C (2010) Reforming long-term care policy in France: private-public complementarities, Social Policy and Administration, 44(4), pp.392 - 410 [↑](#footnote-ref-15)
16. Gadsby, E (2013) Personal Budgets and Health: a review of the evidence, PRUComm [↑](#footnote-ref-16)
17. Rowlett, N and Deighton, S (2009) Simplifying direct payments: How Lincolnshire County Council utilised risk management to deliver genuine improvement, Journal of Care Services Management, 3(2) pp.131-143 [↑](#footnote-ref-17)
18. Ridell. S, et al (2006) Disabled People and Direct Payments: A UK Comparative Study, ESRC End of Award Report [↑](#footnote-ref-18)
19. Le Bihan, B and Martin, C (2010) Reforming long-term care policy in France: private-public complementarities, Social Policy and Administration, 44(4), pp.392 - 410 [↑](#footnote-ref-19)
20. Todd, D ‘Personalising the money’ in Newman, S (2009) Personalisation: Practical thoughts and ideas from people making it happen, Brighton: OLM-Pavilion [↑](#footnote-ref-20)
21. Gadsby, E (2013) Personal Budgets and Health: a review of the evidence, PRUComm [↑](#footnote-ref-21)
22. ibid [↑](#footnote-ref-22)
23. ibid [↑](#footnote-ref-23)
24. ibid [↑](#footnote-ref-24)
25. Beer, G, Paxman, J and Morris, C (2013) Personal Health Budgets: a revolution in personalisation; 2020 Health and Denplan [↑](#footnote-ref-25)
26. Ridell. S, et al (2006) Disabled People and Direct Payments: A UK Comparative Study, ESRC End of Award Report [↑](#footnote-ref-26)
27. ibid [↑](#footnote-ref-27)
28. Rummery, K (2008) The role of cash-for-care in supporting disabled people’s citizenship: gendered conflicts and dilemmas in social citizenship, draft only, via ResearchGate [↑](#footnote-ref-28)
29. Gadsby, E (2013) Personal Budgets and Health: a review of the evidence, PRUComm [↑](#footnote-ref-29)
30. ibid [↑](#footnote-ref-30)
31. ibid [↑](#footnote-ref-31)
32. NHS Confederation (2009) Personal health budgets: the shape of things to come? [↑](#footnote-ref-32)
33. Thom, G and Prabhakar, M (2010) Individual budgets for families with disabled children, Final evaluation report: recommendations and implications [↑](#footnote-ref-33)
34. Gadsby, E (2013) Personal Budgets and Health: a review of the evidence, PRUComm [↑](#footnote-ref-34)
35. ibid [↑](#footnote-ref-35)
36. Manthorpe, J et al (2015) Embarking on self-directed support in Scotland: a focused scoping review of the literature, European Journal of Social Work, 18(1), pp.36-50 [↑](#footnote-ref-36)
37. Beer, G, Paxman, J and Morris, C (2013) Personal Health Budgets: a revolution in personalisation; 2020 Health and Denplan [↑](#footnote-ref-37)
38. Wilberforce, M et al (2014) Revisiting the causes of stress in social work: sources of job demands, control and support in personalised adult social care, British Journal of Social Work, 44, pp.812-830 [↑](#footnote-ref-38)
39. Manthorpe, J et al (2015) Embarking on self-directed support in Scotland: a focused scoping review of the literature, European Journal of Social Work, 18(1), pp.36-50 [↑](#footnote-ref-39)
40. The Medicaid Cash and Counselling scheme was piloted in 15 USA states between 1998-2009. The scheme is now more commonly known as ‘Consumer Directed Care’ and operates in some capacity (Medicaid or non-Medicaid) in 49 states. It was originally limited to in-home care provision for those requiring skilled nursing care, who had severe mental impediments (e.g. Alzheimer’s) or who needed help with everyday activities (e.g. washing, dressing, eating). It has since been extended in some states for some people in small group homes or assisted living residences. The purpose of the scheme is to allow users to choose their own care provider, which may include the family. Users are allowed a ‘surrogate decision maker’ but this cannot be the same person who is paid to provide care. Typically, someone would have to apply for Medicaid (monthly income below c. $2,200 and assets below c. $2000, although this varies by state and is higher for a couple) and then apply for Medicaid waiver, allowing for consumer discretion. There may be a waiting list for the waiver. An assessment is carried out at home (disability requirements vary by state), before a monthly total hours of care figure is calculated. The budget allowance is calculated according to the cost of care in the area, and can be adjusted as the user’s care needs change. Some states run specific consumer directed care programmes for people who are not eligible for Medicaid and also for veterans. Source: <https://www.payingforseniorcare.com/longtermcare/resources/cash-and-counseling-program.html> [↑](#footnote-ref-40)
41. Gadsby, E (2013) Personal Budgets and Health: a review of the evidence, PRUComm [↑](#footnote-ref-41)
42. Da Roit, B and Le Bihan, B (2010) Similar and yet so different: cash-for-care in six European countries’ long-term care policies, The Milbank Quarterly, 88(3), pp.286-309 [↑](#footnote-ref-42)
43. Junne, J and Huber, C (2014) The risk of users’ choice: exploring the case of direct payments in German social care, Health, Risk and Society, 16(7), pp.631-648 [↑](#footnote-ref-43)
44. Gadsby, E (2013) Personal Budgets and Health: a review of the evidence, PRUComm [↑](#footnote-ref-44)
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47. Ridell. S, et al (2006) Disabled People and Direct Payments: A UK Comparative Study, ESRC End of Award Report [↑](#footnote-ref-47)
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52. Gadsby, E (2013) Personal Budgets and Health: a review of the evidence, PRUComm ibid [↑](#footnote-ref-52)
53. Manthorpe, J, et al (2011) Self-directed support: a review of the barriers and facilitators, for the Scottish Government [↑](#footnote-ref-53)
54. ibid [↑](#footnote-ref-54)
55. ibid [↑](#footnote-ref-55)
56. ibid [↑](#footnote-ref-56)
57. Junne, J and Huber, C (2014) The risk of users’ choice: exploring the case of direct payments in German social care, Health, Risk and Society, 16(7), pp.631-648 [↑](#footnote-ref-57)
58. Gadsby, E (2013) Personal Budgets and Health: a review of the evidence, PRUComm, Table 2, p. 10 [↑](#footnote-ref-58)
59. Rummery, K (2008) The role of cash-for-care in supporting disabled people’s citizenship: gendered conflicts and dilemmas in social citizenship, draft only, via ResearchGate [↑](#footnote-ref-59)
60. ibid [↑](#footnote-ref-60)
61. Beer, G, Paxman, J and Morris, C (2013) Personal Health Budgets: a revolution in personalisation; 2020 Health and Denplan [↑](#footnote-ref-61)
62. ibid [↑](#footnote-ref-62)
63. Rummery, K (2008) The role of cash-for-care in supporting disabled people’s citizenship: gendered conflicts and dilemmas in social citizenship, draft only, via ResearchGate [↑](#footnote-ref-63)
64. ibid [↑](#footnote-ref-64)
65. ibid [↑](#footnote-ref-65)
66. Carr, S (2011) Personal budgets and international contexts: lessons from home and abroad, Journal of Care Services Management, 5(1), pp.9 – 22 – citing Raibee, P and Moran, N Interviews with early individual budget holders. York: Social Policy Research Unit, University of York, 2008 [↑](#footnote-ref-66)
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69. Carr, S (2011) Personal budgets and international contexts: lessons from home and abroad, Journal of Care Services Management, 5(1), pp.9 - 22 [↑](#footnote-ref-69)
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71. ibid [↑](#footnote-ref-71)
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