



Protocol: Personal Budgeting Interventions to Improve Health and Social Care Outcomes for People with a Disability: A Systematic Review

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BACKGROUND

The Problem

More than a billion people – or about 15% of the world’s population - are estimated to live with some form of disability, and these rates are increasing over time (World Health Organisation [WHO], 2013). The International Classification of Functioning, Disability and Health (ICF), defines disability as an umbrella term for impairments, activity limitations and participation restrictions. According to the WHO, disability is the interaction between individuals with a health condition (e.g., cerebral palsy, Down syndrome, and depression) and personal and environmental factors (e.g., negative attitudes, inaccessible transportation and public buildings, and limited social supports) (WHO, 2013). The WHO (2013) recognises that disability is extremely diverse, but that generally, rates of disability are increasing due to population ageing and a greater prevalence of more chronic health conditions, whilst people with disabilities also have less access to health care services and, therefore, more unmet needs than ever before. There is further evidence to suggest that people with disabilities have lower life expectancies.

The many different needs of people with a disability, learning difficulty or mental health problem tend to be met through a range of activities, which may be described, collectively, as ‘social care’. These might include help with personal hygiene, dressing and feeding, or general life skills such as shopping, keeping active, and socialising (Malley et al., 2012). In recent years, the disability and mental health sectors have witnessed a significant shift towards community-based health and social care services that attempt to place the service user at the centre of decision-making and service delivery. A growing body of policy now describes how people with disabilities should be autonomous and self-determined members of society. The concept of self-determination has its roots in self-determination theory, which is based on human motivation, development and wellness. According to Deci and Ryan (2008) the theory focuses on the type and quality of motivation as a predictor of performance and well-being outcomes, as well as social conditions that are improved by such motivations. Autonomous motivation, in particular (compared to controlled motivation) – whereby intrinsic and extrinsic motivation allows individuals to identify with an activity’s value and integrate it into their sense of self – can lead to better psychological health, performance and a shift toward healthier behaviours. Compared to amotivation, ‘controlled motivation’ can lead to improvements. However, these improvements are limited, since individuals feel pressure to think, feel and behave in certain ways (in order to avoid shame or to gain approval from the external regulation), when functioning under a system of reward or punishment. Self-determination theory also examines the impact of self-determination on life goals and aspirations and can be applied to a wide range of domains, including relationships, work, education and health care (Deci & Ryan, 2008). The findings of a recent

meta-analysis of 184 studies - based on self-determination theory in health care and health promotion contexts – showed positive relationships between the satisfaction of psychological needs, autonomous motivation and positive health outcomes (Ng. et al (2012). A number of more specific studies which have examined self-determination in a sample of people with a disability, found similarly positive outcomes (Perreault & Vallerand, 2007; Saebu, Sørensen, & Halvari, 2013).

One way to achieve self-determination is by means of a personal budget ("Convention on the Rights of Persons with Disabilities," 2006). Personal budgets are rooted in the Independent Living Movement and the associated Independent Living Fund, whereby people with a disability self-directed their support by hiring a 'personal assistant' (PA) to gain more control over their lives and services. While the concept of independent living varies internationally, all approaches emphasise choice and control whilst acknowledging that personal budgets are just one way to achieve their goals (Jon Glasby & Littlechild, 2009). A personal budget, also known as 'individualised funding', is an umbrella term for various funding mechanisms that aim to provide personalised and individualised support services for people with a disability. Whilst the terminology may vary, the principles remain consistent and are based on self-determination, choice and, very often, person centred planning. Thus, personal budgets aim to place the service user at the centre of the decision making process, thereby recognising their strengths, preferences and aspirations and empowering them to shape public services, social care and support by allowing the service user to identify their needs, and to make choices about how and when they are supported (Carr, 2010). As a result, many international governments are recommending personal budgets as a means to empower individual service users or their advocates, whilst ensuring transparency in the allocation and use of resources.

For example, in Ireland, there are several key policy goals (e.g. enshrined in the Value for Money and Policy Review of Disability Services (Department of Health, 2012)) which promote the use of 'individual needs assessments'. These assessments can lead to a personal budget which can then be used to purchase services from within existing (limited) resources (Keogh, 2011). In the UK, personal budgets are common and are facilitated by standardised resource allocation systems that include a robust needs assessment. Furthermore, a social care outcomes framework is in place to monitor how well social care services are delivering the most meaningful outcomes for people with disabilities whilst also addressing any shortcomings therein (Department of Health, 2013). The monitoring process is supported by tools such as the Adult Social Care Outcomes Toolkit (ASCOT) which was used, for example, in an evaluation of personal budgets commissioned by the UK Department of Health (Forder et al., 2012). This tool comprises eight conceptually distinct attributes or domains including: personal cleanliness and comfort; food and drink; control over daily life; personal safety; accommodation cleanliness and comfort; social participation and involvement; occupation; and dignity (Malley et al., 2012).

There are several types of personal budget which can be used to address these kinds of health and social care needs; the two most common involve either a direct payment model or a brokerage service.

A direct payment involves the funds being given directly to the person with a disability, who then self-manages this money to meet their individual needs, capabilities, life circumstances and aspirations (Áiseanna Tacaíochta, 2014b). This may include the employment of a personal assistant to help with everyday tasks and/or the purchase of services from private, voluntary or community service provider organisations (Carter Anand et al., 2012). Direct payments often involve considerable administrative duties for the person with a disability and are more likely, therefore, to be utilised by people with a physical or sensory disability and less so by those with an intellectual or developmental disability. However, in some cases, a person with a mild intellectual disability may have the skills to manage the direct payment, with or without the support of family members or other natural supports (or informal care). More severe intellectual disabilities would most likely require some kind of family/natural support. This review endeavours to determine whether the benefits of direct payments are affected by the type and degree of disability, or indeed the involvement of third parties whether paid or unpaid.

A brokerage model or ‘managed’ personal budget, on the other hand, whilst it provides a similar amount of freedom for the person with a disability around choice and control of services utilised, involves a broker assuming responsibility for administrative tasks and providing support, guidance and information to enable the person to successfully plan, arrange and manage their support services or care plans (Carr, 2010). The tasks of a broker include working with the person with a disability to develop an individual action plan, as well as researching options within the community to fulfil the goals in the action plan. The broker can also assist in negotiating costs with service providers and are available for support of the individual when necessary (PossibilitiesPlus, 2014). Brokerage models tend to have a far reaching impact across service provision and local authority purchasing by encouraging more flexible and innovative solutions for user-orientated services, whilst also influencing the development of payment schemes (Zarb, 1995).

Whilst the involvement of brokers is ongoing, their presence in the life of the individual tends to be more intensive in the initial transition (i.e. from traditional services) and set-up stages. During this period, the broker will help to develop the ‘circle of support’, either from scratch when none currently exists, or by expanding an existing support structure to include extended family members, such as aunts, uncles, cousins, friends and members of the wider community. During this initial period, the broker may also assist in the recruitment of staff for day-to-day support. For this reason, this review will seek to determine whether or not these intervention effects differ based on the level and quality of support available, both paid and unpaid. Some research suggests that the circle of support is integral to the successful

implementation of such an intervention (Curryer, Stancliffe, & Dew, 2015; Fleming, McGilloway, & Barry, 2015b). Furthermore, the quality of paid support may also affect outcomes since the provision of broker/facilitator training has been found to be a successful element of individualised models of support (Fleming et al., 2015b; Lord & DeVidi, 2015).

A third type of model, the Cash and Counselling model, is found predominantly in the US and allows the user the flexibility to choose between a self-managed and a professionally managed/assisted account. This represents a combination of the direct payment and brokerage models described above (National Resource Center for Participant-Directed Services, 2014). In many jurisdictions, the brokerage/support function which facilitates planning and implementation, is separated from the ‘fiscal management’ supports which handle the accounting and human resource issues, but not the personal planning/support/monitoring element. While these can be conflated in some cases, it is generally considered important to maintain the independence of the brokerage/planning function from the fiscal dimension to avoid conflict of interest. The separation of the two allows individuals or advocates who do not wish to have any planning support to secure the ‘payroll’ services required without any obligation to avail of planning and monitoring supports.

While ‘individualised funding’ is emerging as an umbrella term for the various funding mechanisms, terminology remains unclear. A decade ago, ‘cash-for-care’ or ‘cash and care’ were predominant umbrella terms when reviewing evidence over several decades from the US, UK and EU (Caroline Glendinning & Kemp, 2006; Ungerson & Yeandle, 2008). These early studies highlighted the risks associated with the marketisation and indirect privatisation of care services whereby ‘consumers of care’ increasingly act as employers without necessarily having the human resource skills or knowledge of available care choices (Woods, 2008). In contrast, evidence suggests that people availing of personal budgets are capable of acquiring the necessary skills, or indeed able to outsource certain tasks in order to successfully bypass the service providers and contract their support services directly (Fleming et al., 2015b). Thus, there exists a tension between individuals with a disability, who can secure potential cost savings while having more autonomy, and traditional service providers who need to maintain contractual agreements with staff members within their organisations.

Further tensions may also exist for frontline staff between their ethical obligations to promote empowerment and self-determination whilst honouring their legal obligations to limit access to personal budgets (Ellis, 2007). Another challenge for staff relates to risk management. A balancing act is required to facilitate positive risk-taking whilst ensuring that the personal budgeting-specific risks, such as financial abuse, neglect or physical/emotional abuse, are avoided. This requires careful consideration and planning, but risk management can vary considerably. For example, during the piloting of personal

budgets in the UK, local authorities conducted risk assessments but in some cases relied on annual reviews, thereby placing the onus of responsibility on individuals or families in the interim (C. Glendinning et al., 2008). Carr and Robbins (2009) also highlight the region-specific contextual factors, such as culture and policy, which can influence implementation of personal budgets. For example, in Canada, the US and the Netherlands, it is compulsory to use an independent support broker, whilst in the UK and US, ‘personal assistants’ are the preferred option for those receiving personal budgets. The eligibility criteria may also differ at initial implementation depending on the region. For example, in Canada, the focus was on younger people with learning disabilities whereas the Swedes focused on adults with physical disabilities; furthermore, very few regions accommodated people with mental health problems. Objectives also differed; for example, Australia initially focussed on tackling fragmented service provision, particularly in rural areas, while the US concentrated on solving staff shortages in long-term care facilities (Carr & Robbins, 2009).

All of the above interventions, regardless of delivery mode, involve a transitional period which can be difficult for individuals and families to manage, particularly when national systems of allocating resources are not in place and families have to negotiate the release of funds from a regional disability manager, as is the case, for example, in Ireland (Fleming et al., 2015b). This period of transition can also be a time of great uncertainty for individuals and their families (where applicable) who have left a form of service provision to which they have been accustomed, often for many years. As a result, the length of time that the intervention has been in place may considerably affect its real or perceived effects. Furthermore, socio-demographic factors may have a similar impact; for example, an older person may have been using traditional forms of services for much longer than a young adult transitioning from mainstream school or another form of secondary education. Thus, past experiences, such as institutionalisation, may dramatically affect an older person’s ability to adapt to this new model of service provision. Equally, more people living in rural areas have been found to avail of day services when compared to urban dwellers, potentially due to a lack of alternatives within the community (Fleming, McGilloyay, & Barry, 2015a). This dependence on traditional day services may impact an individual’s ability to adjust to the new model, or could limit the potential for community integration due to a lack of community services for the general population. Therefore, this review will take such confounding factors into consideration, both in the inclusion/exclusion criteria and in the subgroup analysis.

The Intervention

For the purposes of this review, the intervention will include any form of personal budget, regardless of the name given to the model of delivery. As indicated above, these models may be described in many different ways. For example, Webber et al. (2014) identified: ‘Individual Budgets’; ‘Recovery Budgets’; ‘Personal Budgets’; ‘Direct Payments’; ‘Direct

Health Budgets’; and ‘Cash and Counselling’. Others include ‘third party managed’ personal budgets, direct payments managed by an appointed person and individual service funds. However, a personal budget, to be included in this review, must have the following fundamental characteristics: (1) It must be provided by the state as financial support for people with a physical, sensory, intellectual, developmental disability or mental health problem; (2) the recipient must be able to freely choose how this money is spent in order to meet their individual needs; (3) the individual can avail of “brokerage” services or any equivalent service which supports them in terms of planning and managing how the money is used over the lifetime of the funding period; (4) the recipient can also independently manage the personal budget, in whatever way is feasible, such as setting up a “Company Limited by Guarantee” as is the case in Ireland (Áiseanna Tacaíochta, 2014a); and (5) the personal budget may be provided as a ‘once-off’ pilot intervention for a defined period of time (minimum 6 months), or it can be a permanent move from more traditional forms of funding arrangements that exist nationally or regionally.

Personal budgeting interventions are implemented with a view to delivering a range of positive health and social care outcomes over time. It is expected that a persons' quality of life will improve (e.g. socially, personally, environmentally and in terms of their physical / psychological health) as a result of their increased autonomy, choice and control over daily life decisions and greater social integration and interaction. Client satisfaction is also expected to improve due to greater self-determination. By increasing independent life skills (i.e. taking on more responsibilities such as shopping and household chores) physical functioning also has the potential to improve. Many of these quality of life measures if improved, would arguably generate greater cost benefits, although evidence is limited. The limited pool of evidence would suggest that personal budgets can be cost effective, ranging from 7% to 16% in the US (Conroy, Fullerton, Brown, & Garrow, 2002) to 30% to 40% in the UK (Zarb & Nadash, 1994). In contrast, another UK study suggested that personal budgets may not result in cost savings but do represent value for money (John Glasby & Littlechild, 2002). Stainton, Boyce, and Phillips (2009) support these more conservative findings showing relative cost neutrality for personal budgets compared to independent service providers, however personal budgets were more cost effective than traditional in-house service provision. Furthermore they reported greater user satisfaction for those availing of personal budgets, highlighting the link between client satisfaction, quality of life and cost benefits.

Rationale for the Intervention

The international move towards personal budgets has led, in turn, to a growing interest in identifying methods, more generally, that might offer the most potential in terms of informing effective and efficient resource allocation, particularly in the context of recent economic reforms. However, these strategic and policy decisions would appear to be evolving

on the basis of locally sourced or anecdotal evidence, since there appears to be a lack of high quality experimental studies in the area (Webber et al., 2014). Nonetheless, current international evidence suggests many benefits of personal budgets, such as increased choice and control, and a positive impact on quality of life (QoL), cost effectiveness and reduced service use (Field, 2015; Webber et al., 2014). A theory of change seeks to explain the pathways/mechanisms that lead to change (in this case positive change) and to determine the links between activities, outputs and outcomes (Taplin, Clark, Collins, & Colby, 2013). In the case of personalised budgets, people with disabilities are meant to have more autonomy over their lives (e.g. by having a say in every decision that affects them) which, in turn, acts as a mechanism to enhance self-determination, something that most people without a disability take for granted. A mantra that resonates globally within the disability sector is “Nothing about us, without us” (Charlton, 1998). This aptly illustrates the fundamental need to place the person with a disability at the centre of decision making. Thus, personal budgets and attendant services are designed as a vehicle/mechanism for potentially improved health and social care outcomes. Such individualised funding arrangements are also important in shifting the power dynamic from service providers and placing it in the hands of individuals with a disability (or their families).

Glendinning et al. (2008) reported mixed findings in their RCT on the impact of a personal budget on health, social care and personal outcomes within their subgroup analyses. Outcomes varied according to age or mental health status, whilst the type of disability did not appear to play an important role (C. Glendinning et al., 2008). Furthermore, health outcomes may vary across various jurisdictions where different rules exist on what can or cannot be funded from a personal budget – particularly health services which may have different eligibility rules by region. Importantly, international evidence on personal budgeting models suggests that there is no ‘one size fits all’ approach for everyone; hence, there is considerable variation with regard to: levels of choice and control given to service users; the professionals involved; the type of funder; and the limitations in both the services available for purchase and administrative structures/ processes (Carter Anand et al., 2012).

It is notable that the type of study design also varies considerably in the evaluation of personal budgets. Studies include, but are not limited to: RCTs (C. Glendinning et al., 2008; Shen et al., 2008); quasi-experimental trials with controls (Forder et al., 2012; Foster, Brown, Phillips, & Schore, 2003; Teague & Boaz, 2003); and without controls (Spaulding Givens, 2011); cross-sectional surveys (Hatton & Waters, 2011; Lawson, Pearmain, & Waters, 2010); and qualitative studies (Coyle, 2009; Homer & Gilder, 2008; Maglajlic, Brandon, & Given, 2000).

Prior Reviews

We are aware of only two reviews, to date, which have specifically examined personal budgets for people with a disability or mental health problem. Both of these included quantitative and qualitative data. The first, by Carter Anand et al. (2012), was a rapid evidence assessment rather than a rigorous systematic review. As a result, the search strategy had some major limitations, such as the exclusion of non-English studies and a geographical restriction to 7 countries including: the United States; Australia; Germany; Great Britain; Ireland; Netherlands and New Zealand. The authors acknowledged that the search strategy had resulted in a limited evidence base, which precluded the possibility of drawing strong conclusions about the implementation and impact of personal budgets. However, they also indicated that the qualitative evidence derived from service users tended to reflect positive views about the initiatives. The review did not report on the characteristics of included studies, or on study results in any detail. Furthermore, there was no detail about whether or not a meta-analysis was conducted, or the methods by which the qualitative data were synthesised. In addition, no subgroup analyses were conducted despite an apparent broad definition of disability (e.g. various types and level of physical and intellectual disabilities, inclusion of older people and those with mental health problems). Finally, while quality was assessed, no information was provided on any assessment of bias.

The second more recent review by Webber et al. (2014) closely followed the EPPI-Centre methodology for conducting a systematic review, appraising methodology and assessing the research quality and reliability (Gough, Oliver, & Thomas, 2012). Once again however, non-English studies were excluded, but more importantly, the focus of this systematic review was on mental health only; other physical or learning disabilities were included only if they co-existed with mental health problems. Fifteen studies were included in the review and the main findings showed that personal budgets can have positive outcomes for people with mental health problems in terms of choice and control, impact on QoL, service use and cost-effectiveness (Coyle, 2009; Davidson et al., 2012; C. Glendinning et al., 2008; Spandler & Vick, 2004). However, methodological shortcomings, such as variation in study design, sample size, and outcomes assessed, were reported to limit the extent to which the study findings could be accurately interpreted or generalised. This was compounded by considerable variation in the support models included, but without any attempt to undertake a sub-group analysis (e.g., 'Personal Budget' versus 'Direct Payment' versus 'Recovery Budget' versus 'Cash and Counselling'). Consequently, the authors concluded that more large, high quality, experimental studies were required before any definitive conclusions could be reached (Webber et al., 2014).

Contribution of this Review

We are not aware of any systematic review that focuses on the effectiveness of personal budgets in relation to people with a disability of any form, including mental health problems. Given the new policy imperative around personal budgets and the growing pool of studies in this area, there is now a need for a systematic review of these models (when compared to a control) across a spectrum of disabilities, in order to assess their effectiveness in relation to health and social care outcomes. A supplementary synthesis of the non-controlled evaluations and qualitative studies will also be included in order to capture these valuable findings in an area that is relatively new. Due to the complex nature of implementing innovative initiatives that challenge the status quo, many qualitative studies have been undertaken to capture important perspectives, successes and challenges and these cannot, therefore, be overlooked in this review.

This review will: (1) assess the effectiveness of personal budgeting interventions; (2) utilise subgroup analyses to explore how effects may differ by various client and intervention parameters; and (3) appraise and synthesise the experiences of key stakeholders. The ultimate aim of this review is to provide useful, robust and timely data to inform service providers/organisations working in the field of disability and to provide a rigorous evidence base on which decisions by policy makers (and drivers) can be made around different resource allocation/personal budgeting models to support greater choice and control by individuals in their daily lives.

OBJECTIVES OF THE REVIEW

The objectives of this review are to: (1) examine the effectiveness of personal budgeting interventions for adults with a disability (physical, sensory, intellectual, developmental or mental disorder), in terms of improvements in their health and social care outcomes when compared to a control group in receipt of funding from more traditional sources; and (2) to critically appraise and synthesise the qualitative evidence relating to stakeholder perspectives and experiences of personal budgets, with a particular focus on the stage of ‘initial implementation’ as described by Fixsen and colleagues (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005). Most interventions included in the synthesis, at a minimum, should have reached initial implementation. Unsurprisingly, this is often the most challenging stage of implementation. Fixsen et al (2005) describe initial implementation as complex, requiring ongoing / multi-level change (e.g. individual, environmental and organisational) that is not necessarily linear and which is influenced by external administrative, educational, economic and community factors. As a result, it is during this stage that stakeholders can experience the most fear of change or inertia. The next stage of implementation, ‘full operation’, cannot be initiated until the challenges associated with

initial implementation are overcome and associated learnings are integrated into policy and practice.

Key questions include:

- What model of personal budget (e.g., direct payment or brokerage) is relatively more effective at improving health and social care outcomes?
- Do support structures such as resource allocation systems, needs assessments, support planning and review affect intervention effectiveness?
- How is the intervention effect linked to length/intensity of intervention?
- Is the intervention effect linked to type and/or severity of presenting disability (e.g., physical, sensory, intellectual, developmental or mental disorder)?
- Is the effect linked to implementation fidelity (e.g. does level of staff knowledge, access to independent information, advice, training and support affect intervention effectiveness)?
- Does the effect differ depending on the level of support available from non-paid advocates (e.g., friends and family)?
- Do socio-demographic factors, (e.g., age, race/ethnicity, sexual orientation, gender, religious beliefs, household income, urban/rural setting) impact on intervention effectiveness?
- What are the experiences, barriers and facilitators associated with the implementation of personal budgeting initiatives for people with a disability or mental health disorder?
- What is the economic impact of the intervention from both a service user and public service perspective?

METHODS

Characteristics of the Studies Relevant to the Objectives of the Review

Eligible study designs for questions relating to the effectiveness of the personal budgeting intervention will include randomised, quasi-randomised and cluster-randomised controlled trials. Due to the complex nature of the intervention and attendant ethical constraints, randomisation may not be possible since the aim of personal budgets is to increase choice and control, and randomisation limits this option. Therefore, non-randomised studies (e.g., controlled before and after studies, cross-sectional surveys, longitudinal studies or cohort

studies) will be considered in this part of the review. Randomised and non-randomised studies will be analysed separately. We will not include single-case designs, pre-post studies without a control group, non-matched control groups, or groups matched post-hoc after results were known.

For the qualitative synthesis, eligible studies will include: ethnographic research; phenomenology; grounded theory; participatory action research; case studies; or mixed methods studies if qualitative methods have been used to gather data. Methods used to collect the qualitative data in primary studies will include: interviews; focus groups; observation; open-ended survey questions; and documentary analysis.

Criteria for Inclusion and Exclusion of Studies in the Review

For the quantitative element of this review, where a control group exists, support services may take two forms: (1) traditional ‘services as usual’ (e.g., predetermined group activities, provided in a congregated setting and financed through block funding to service providers whereby previous annual spend for a service provider is used to estimate the required funding for the upcoming year (National Disability Authority, 2011); or (2) a different type of personalised support which does not include a personal budget where, for example, a service user might access services through a congregated setting where finances are centralised, but where an individualised plan is used to determine service user needs and preferred activities. However, the individualisation of planned responses may be limited, for example, by majority preferences within the group, staffing limitations or pre-existing service options.

We will exclude personal budgeting interventions that are provided to families, guardians/ other carers, or where the person with a disability does not have an active role in the decision making and planning process and cannot exercise control over the use of funds. However, studies may be included where an advocate is managing the funds after an individual assessment of need takes place and provided that the funds are being used to meet the needs identified during the assessment.

A personal budget which is provided by the persons' family or another private means will not be included, as this review is interested in the use of public funds for people with a disability. Furthermore, private sources of funding introduce confounding factors which would lead to uncontrollable bias.

Intervention

Any form of personal budget or individualised funding which is state funded directly or indirectly.

Population Inclusion criteria

- Adults aged 18 years and over receiving a personal budget
- Where the study has categorised the person as having:
 - any form or level of physical, sensory, intellectual or developmental disability
 - any form or level of mental health problem, disorder or illness
 - dementia
- Residing in any country
 - Residing in any type of residential setting (own home, group home, residential care setting, nursing home, hospital, institution)

Population Exclusion criteria

- Minors under the age of 18 since the decisions around their daily lives are ultimately made by a parent or legal guardian.
- Privately funded personal budgeting interventions.

Primary Outcomes

The primary outcomes of interest (i.e. pertaining to the quantitative studies) are ‘Quality of Life’ and ‘Client Satisfaction’. Each is described in more detail below.

- **Quality of Life**, including: physical health; psychological health; well-being; social relationships; personal and life satisfaction; and environment or disability-specific QoL including: choice; control over daily living; autonomy; social acceptance; social network and interaction; social inclusion and contribution; future prospects; communication ability; safety and personal potential. Typical measures include the WHO Quality of Life Disability module (WHOQOL-DIS) (Power & Green, 2010) and the Adult Social Care Outcomes Toolkit (ASCOT) (Malley et al., 2012).
- **Client satisfaction**, as measured by access to and continuity of care, shared decision making, level of choice, control and self-determination, planning, co-ordination and review of care, respect shown, information provided, staff attitudes and responsiveness, physical and emotional comfort; encouragement, opportunities for positive risk-taking, risk management, availability of services, staff training and management, cost and administrative burden. The Consumer Assessment of Healthcare Providers (CAHPS) is an example of a set of satisfaction scales which measure and evaluate various aspects of consumers’ experiences of health care, including a tool for measuring: health plans; group and individual service providers;

hospitals; nursing homes; and behavioural health services (Kane & Radosevich, 2011b).

Secondary Outcomes

- **Physical functioning**, measured by Activities of Daily Living (ADL), such as: bathing; dressing; feeding; transfer; toileting or advanced independent living activities such as: shopping; doing chores; and cleaning. These can be measured using, for example, the Katz Index of ADLs (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963 as cited in Kane & Radosevich, 2011a).
- **Financial data**, measured for example by: size of personal financial package available; brokerage/management fees; cost of individual services; and cost of recruiting staff (for self-managed).

Adverse Outcomes

- **Adverse Psychological Impact**, as measured by symptoms of depression, anxiety, stress, social dysfunction, and feelings of isolation. Depression can be measured as clinical (for example the Hamilton Rating Scale) or non-clinical depression (e.g., Carroll Rating Scale) (Kane & Radosevich, 2011a) or can be disability specific (e.g., Glasgow Depression Scale for people with a Learning Disability) (Cuthill, Espie, & Cooper, 2003). Anxiety may have been measured for example by general anxiety scales such as the Anxiety Adjective Checklist or Zung's Self-Rating Anxiety Scale (Kane & Radosevich, 2011a) or the Glasgow Anxiety Scale for people with a learning disability (Hermans, van der Pas, & Evenhuis, 2011).

Qualitative Outcomes

- For the qualitative synthesis, outcomes or phenomena of interest will involve the experiences of stakeholders in receiving and implementing a personal budget. Stakeholders include the client, family members, advocates, personal assistants / key workers, professional staff such as occupational therapists or physiotherapists and other members of the community involved in the process.

Search Strategy for Finding Eligible Studies

The Campbell Collaboration policy brief for searching studies and information retrieval, informed the search strategy as presented below (Hammerstrøm, Wade, Hanz, & Klint Jørgensen, 2009). In addition, an information retrieval specialist within Maynooth University was consulted during the preparation of search strings. Padraic Fleming, the lead author, will conduct the searches once the protocol has been peer-reviewed and approved by

Campbell Collaboration. It is expected that searches will be conducted in the first quarter of 2016; exact dates will be reported. Studies in any language and from any country will be reviewed for inclusion, provided the abstract is in English.

As recommended by Higgins and Green (2011), the search strategy will be reported in an appendix of the systematic review. This will be reported separately for each database utilised and will be copied and pasted exactly as it was performed. This will ensure that all searches are reproducible. Examples of copied and pasted search strings are provided in Appendix A.

Electronic Search

A selection of electronic search databases relevant to the area of study will be searched. Where available, database thesauri will be used to identify database specific terms for inclusion. These terms will be “exploded” to encompass all narrower terms when appropriate to do so. These terms will also help in the identification and inclusion of all possible synonyms. In addition to these database specific terms, free text terms which have been identified from within the current literature will be used to further broaden the search.

It is planned to search the following databases/search engines:

1. CINAHL (Cumulative Index of Nursing and Allied Health Literature)
2. EMBASE
3. Medline Ovid
4. ASSIA (Applied Social Sciences Index and Abstracts) (Centre for Reviews and Dissemination, 2009)
5. PsycInfo
6. SCOPUS
7. Sociological Abstracts
8. Worldwide Political Science Abstracts
9. EconLit with Full text
10. Business Source Complete
11. Greylit
12. OpenGrey.eu

13. ProQuest Dissertations and Theses

14. Google Scholar

15. Google

Search Terms

The terms used to customise the search string for specific databases are based on the ‘population’ and ‘intervention’ of interest. “Disability” and all possible variations including mental health, disorders and autism is the first keyword. Where available, database-specific terms will be used, encompassing all types of disability (see extensive list for PsychInfo – Appendix A). Where an overarching term, encompassing all disabilities is available, this will be exploded (see Embase search string in Appendix B). “Budget” and all variations of same is the second keyword. The following truncations: “person*”; “individ*”; and “self-direct*” may be used to narrow the results relating to the main keywords, when necessary, connecting them to the main keywords with, for example, “near/n” or “w/n”, where possible. All other keywords will be connected with “or”/”and” when searching titles and abstracts. Where appropriate search terms will also be truncated to allow for variations in word endings and spellings. Truncation conventions will be specific to the database searched. A list of free-text terms which have been identified in the literature will also supplement the syntax developed. Individual studies and systematic reviews already known to the authors were used to check the sensitivity of search strings developed (Carter Anand et al., 2012; Webber et al., 2014).

Study design and outcomes will not be included as part of the search strategy as it is anticipated that this would potentially lead to the omission of relevant literature. Furthermore, the mixed methods approach of this review has led to a broad inclusion criteria for study design.

All search strings can be seen in Appendix A. Outlined below is a sample search string:

'intellectual impairment'/exp OR 'disability'/exp OR handicap OR ((people OR person* OR individ*) NEAR/3 (disabil* OR disable*)):ab,ti OR insanity OR (mental NEAR/1 (instability OR infantilism OR deficiency OR disease OR abnormality OR change OR confusion OR defect* OR disorder* OR disturbance OR illness OR insufficiency)):ab,ti OR (psych* NEAR/1 (disease OR disorder* OR illness OR symptom OR disturbance)):ab,ti AND ('financial management'/exp OR ((budget OR finance* OR fund* OR resource OR money OR income OR purchas* OR broker* OR salary OR capital OR investment OR profit) NEAR/3 (individual* OR person*)):ab,ti) OR 'cash for care':ab,ti OR 'consumer directed care':ab,ti OR 'direct payment':ab,ti OR 'indicative allocation':ab,ti OR 'individual budget':ab,ti OR 'individual service fund':ab,ti OR 'managed account':ab,ti OR 'managed budget':ab,ti OR

'notional budget':ab,ti OR 'personal budget':ab,ti OR 'personal health budget':ab,ti OR personalisation:ab,ti OR 'personalised care':ab,ti OR personalization:ab,ti OR 'person centred':ab,ti OR 'pooled budget':ab,ti OR 'recovery budget':ab,ti OR 'resource allocation system':ab,ti OR 'self-directed assessment':ab,ti OR 'self-directed care':ab,ti OR 'self-directed support':ab,ti OR 'support plan':ab,ti OR 'virtual budget':ab,ti OR 'disability living allowance':ab,ti AND [1985-2015]/py

Grey Literature

An international list of grey literature databases published within the Campbell Collaboration policy brief on searching for studies was consulted (Hammerstrøm et al., 2009). A US electronic database, run by The New York Academy of Medicine, dedicated to specifically searching grey literature in public health will be employed (www.greylit.org). Opengrey.eu will also be used to search grey literature in Europe. Boolean operators are not supported by these databases; therefore keywords, based on the database searches of published work, will be searched separately (Appendix A). Similar search strategies will be employed for other country / region specific sites such as Australian Policy Online or Trove a grey literature database provided by the National Library of Australia. Hammerstrøm et al (2009) suggest national databases containing country specific articles which may not be indexed elsewhere. These suggested databases will also be searched.

Timelines and other restrictions will not be imposed in order to maximise the results from grey literature. Reference lists from relevant studies and previous systematic reviews will be visually scanned to pick up on unpublished literature not previously identified. Google Scholar, the popular internet search engine, will also be used to search the terms developed for the academic databases in order to identify any relevant web materials or organisational/governmental reports which are unpublished or not accessible through electronic databases. ProQuest Dissertations and Theses will also be used to search for relevant theses at doctoral and masters level. Finally, Google search engine will be searched to identify any relevant conference proceedings and government documents in addition to relevant NGOs that may have relevant research materials unpublished elsewhere. The first 500 webpages of Google and Google Scholar will be scanned, amounting to around 6,000 references per search engine.

Cross-referencing of bibliographies

The references of each of the final studies included in the review will be imported into Endnote reference manager and scanned to identify any potentially relevant studies that have not already been appraised. The bibliographies from the two previous reviews will also be cross-referenced (Carter Anand et al., 2012; Webber et al., 2014).

Conference proceedings and experts in the field

Conference proceedings such as the extensive syllabus from the recent international conference hosted by The University of British Columbia's Centre for Inclusion and Citizenship ('entitled Claiming Full Citizenship: Self Determination, Personalization, Individualized funding) will be consulted. This syllabus provides slides from over 100 presentations and contact details for research and practice experts from around the world who specialise in the delivery of individualised funding, self-determination and personalisation of services for people with a disability. This syllabus will be used as a reference point for identifying and potentially sourcing data from unpublished or ongoing studies.

Corresponding authors as listed on published works will be contacted, where necessary, to access primary data, or for clarification purposes during the data extraction process.

Timeframe (and other filters)

According to Leece & Leece (2011), the origins of personalised brokerage schemes and personal budgets can be traced back to the mid-1980s in to the USA. Around the same time (1988), legislation in Western Australia introduced a form of personal budget known as the Local Area Coordination charter which facilitated a mechanism for "Direct Consumer Funding" (Carter Anand et al., 2012). For this reason, the searches of published literature will be limited to the period 1985 – 2015. The end date for the review will extend to quarter one of the current year (2016) in order to capture the most recent publications. For example, date filters were applied to the Scopus search results (Appendix A). Other filters may also be applied where it is necessary to refine the search, such as exclusion of non-relevant subject areas (See Embase search string Appendix A).

Manually browsing key journals

Toward the end of the data retrieval process, the most recent issues of key journals (i.e. those that produced the most studies in the meta-analysis) will also be browsed manually to capture any relevant work that has been published since the searches were last run.

Data Extraction and Study Coding Procedures

Titles will be reviewed initially in Endnote by the lead author to remove any studies which are clearly irrelevant (e.g. non-human or pharmaceutical studies). Excluded studies will be reported (see sample flowchart in Appendix B). Following this, the screening of studies in relation to inclusion/exclusion will be undertaken in two stages. The first stage will involve citation and abstract; the second will involve full text documents. Two independent researchers will be involved at each stage. Both (PF & MH) are co-authors of this protocol and have a deep understanding of the research questions and outcomes of interest. However, prior to data extraction and coding, the two independent reviewers will meet to discuss and

pilot the extraction and coding procedures on a sample of abstracts. A third party (SMcG) will resolve any disagreements between the two independent researchers, where a resolution cannot be agreed through discussion and consensus. Inter-rater reliability will be calculated on a sub-sample of papers using kappa statistic, as recommended and will be based on making simple inclusion/exclusion decisions. Values of kappa between 0.40 and 0.59 reflect a fair level of agreement between reviewers, whilst values from 0.60 to 0.74 reflect good agreement; 0.75 indicates excellent agreement (Higgins & Green, 2011; Chapter 7.2.6). The inter-rater reliability score will be recorded and if there is a considerable level of disagreement, the reviewers will revisit the eligibility criteria and coding schemes together to ensure consistency in interpretation.

To pre-empt such disagreements, both reviewers will discuss the inclusion/exclusion criteria and the various tools being used to assess study quality and risk of bias. Any potential differences in interpretation will be discussed and resolved insofar as possible. A number of known studies will be used to pilot the data extraction and coding procedures in order to support this process.

Stage one: citation and abstract

Citations and abstracts which pass the first stage will be retrieved in full text for a more comprehensive review. In order to pass stage one the citation or abstract must answer 'Yes' or 'Unsure' to all the questions below:

- a) Has a personal budgeting intervention been utilised?
- b) Is the study population aged over 18 years of age?
- c) Does the study population have any form of physical, sensory, intellectual or developmental disability, dementia or mental health problem, disorder or illness?
- d) Does the personal budget originate from public funds, directly or indirectly?
- e) Has a study design been adopted which collected and analysed empirical data?

If reviewers are unsure, full text articles will be retrieved to clarify.

Stage two: full-text

Full text documents will be retrieved for all documents which pass stage one. Two reviewers will independently evaluate all studies. In order for the studies to advance to full review, they must meet all the inclusion/exclusion criteria set out previously. Reasons for exclusion will be independently reported by both reviewers in the 'research notes' field within endnote reference manager. For studies that will be included in the review, a standard set of data will

be reported such as: eligibility criteria, publication details; study summary, study design; participant, intervention and control descriptors; and outcome measures and effect size (see Sections A-H, Table 1 in Appendix C). Data extraction will be duplicated by two independent reviewers.

Risk of Bias

Risk of bias will be evaluated using a range of tools (depending on study design) by two independent reviewers (PF and MH). The main areas of bias include: selection bias; performance bias; detection bias; attrition bias; and reporting bias (Higgins & Green, 2011; Chapter 8). ‘The Cochrane Collaboration’s tool for assessing risk of bias’ (Table 2 in Appendix C) will be used to appraise randomised, quasi-randomised and cluster-randomised controlled trials. All non-randomised study designs will be appraised for quality and risk of bias using the appropriate tool from the Critical Appraisal Skills Programme (CASP). CASP consists of a set of eight critical appraisal tools designed to read and check health research for trustworthiness, results and relevance, specifically for systematic reviews, randomised controlled trials, cohort studies, case control studies, economic evaluations, diagnostic studies, qualitative studies and clinical prediction rule. (Critical Appraisal Skills Programme (CASP), 2014)

The overall quality of the evidence will be reported using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) for quantitative data and Confidence in the Evidence from Reviews of Qualitative research (CerQual) (Lewin et al., 2015). GRADE takes into consideration: within-study risk of bias (methodological quality); directness or relevance of evidence; heterogeneity; precision of effect estimates; and risk of publication bias (Higgins & Green, 2011; Chapter 12.2.1). A ‘high’ GRADE score indicates further research is unlikely to change reviewer’s confidence in the estimate of effect, while a ‘low’ score indicates further research is very likely to impact reviewer’s confidence and the estimate of effect. CerQual scores are based on methodological limitations, relevance, adequacy of data and coherence and are also scored from high to very low (Lewin et al., 2015).

The risk of bias score and GRADE / CerQual score will be reported in Section I of Table 1 along with an explanation to support the score based on evidence from primary studies (Appendix C).

Synthesis Procedures and Statistical Analysis

The main study findings, limitations, risk of bias and evidence quality score will be reported in Table 1 (Appendix C). A meta-analysis of data will be conducted using RevMan for all quantitative studies included in the review, Stata will be used for data that require analysis prior to the meta-analysis (Review Manager (RevMan), 2012; StataCorp, 2013). When

inputting data, numerical accuracy, including magnitude and direction of effect will be checked. Initially, summary statistics will be presented for all studies and the appropriate effect estimates reported. Randomised and non-randomised studies will be analysed separately. It is expected, however, that there will be a range of intervention models and outcome measurements utilised, as outlined previously. Study results will therefore be organised in a hierarchy as recommended by the Cochrane Collaboration (Higgins & Green, 2011; Chapter 4.8). As highlighted by Webber et al (2014) there is no ‘one size fits all’ approach to individualised funding, hence the various mechanisms used to deliver services. Therefore, provided that sufficient studies have been identified, studies will first be pooled and analysed within subgroups such as: brokerage; direct-payment; cash for counselling. However, if a sufficient number of studies has not been identified to allow reliable estimation of random effects mean and variance, then all studies will be analysed together regardless of the mechanism of delivery, calculating the mean effect for each outcome such as: Quality of Life, Client Satisfaction, Adverse Psychological outcome etc. (Higgins & Green, 2011; Figure 4.8a) Intervention type will then be used as a moderator in the subgroup analysis.

Continuous data

Continuous data will most likely be reported in the quantitative studies, with health and social care outcomes most likely measured using scales. Where these scales are the same across studies, the summary statistics used in the meta-analysis will be mean differences between groups i.e. what was the differences in mean scores between groups. Where scales differ across studies, standardised mean differences will be used to combine effect sizes across studies. Studies may present their results using statistics such as p values, standard errors, confidence intervals or t values. Where this is the case, standard deviations / effect sizes will be calculated using the appropriate steps based on the available data (Higgins & Green, 2011; Chapter 7.7.3) and the RevMan calculator (Review Manager (RevMan), 2012). Where this is not possible, authors will be contacted for missing information. In cases where standard deviations are unavailable and cannot be calculated, we will impute an average standard deviation from other included studies as this method has been found to produce approximately correct results (Higgins & Green, 2011; Chapter 16.1.3.1). Effect sizes will be calculated and reported using a point estimate and the associated 95% confidence interval. A relatively narrow interval will suggest that the point estimate is quite precise, with the opposite interpretation for intervals that are very wide. Effect sizes will then be weighted, giving more weight to the studies reporting narrower intervals (Higgins & Green, 2011; Chapter 8.8.4.1).

Dichotomous data

Where binary or categorical data is used to compare intervention and control groups for effect estimates, risk ratios will be summarised using a 95% confidence interval. Higgins and

Green (2011) report little difference between the consistency of odds ratio and risk ratio; however odds ratios are more difficult to interpret with the potential for the effects of an intervention to be overestimated .

Combining data

In the event that different studies examining the same outcome (e.g. ‘quality of life’) use dichotomous and continuous data, then these data will be combined. If possible, additional data will be sought from study authors in order to recalculate and report data in a similar way. If additional data are not available, then the data will be re-expressed as either continuous or dichotomous, depending on which data type represents the majority of studies.

Due to expected heterogeneity of study characteristics, a random-effects model will be employed for both dichotomous and continuous outcomes. This model assumes that the effects being estimated in the different studies are not identical, but that they do follow some distribution. The random-effect model is based on the inverse-variance approach which makes an adjustment to the study weight according to the variation between the different intervention effects (Higgins & Green, 2011; Chapter 9.4.3). In order to utilise this model, standard errors are required. Therefore, odds ratios can be expressed as standardised mean differences by calculating the log odds ratio. Standard error of log odds ratio can then be calculated. Conversely standardised mean difference can be translated into log odds ratios if necessary. Once these conversions have been made for all studies, the data can be entered into RevMan in order to complete a meta-analysis using standard errors (Higgins & Green, 2011; Chapter 9.4.6).

Heterogeneity analysis

Study heterogeneity will be analysed and reported using outputs from RevMan for overall and subgroup analysis. Heterogeneity will be assessed by comparing study characteristics such as type of intervention and control comparators, participant demographics, quality of trials (randomisation, blinding, losses to follow-up) and outcomes measured. Statistical heterogeneity will be assessed visually and by examining the I^2 statistic, which describes the approximate proportion of variation that is due to heterogeneity rather than sampling error. This will be supplemented by the Chi^2 test, where a P value < 0.05 indicates heterogeneity of intervention effects. In addition, we will estimate and present Tau^2 , along with its CIs, as an estimate of the magnitude of variation between studies. This will provide an estimate of the amount of between-study variation. Sensitivity and subgroup analyses will also be used to investigate possible sources of heterogeneity. If severe heterogeneity is found, the data entered into RevMan will be double checked to ensure accuracy of mean effect transformations (if applicable).

Sensitivity analysis

A sensitivity analysis will be conducted to evaluate the robustness of the meta-analysis by assessing the impact of a single study or subgroups. This will be carried out by removing studies which have a high risk of bias overall. The impact of moderating study characteristics may also be considered in the sensitivity analysis, such as sample size, use of average standard deviations, skewed or missing data. Individual peculiarities which are identified during the review process will also be introduced into the sensitivity analysis, if they arise (Higgins & Green, 2011). For studies that include data considered to be skewed, the original papers will be consulted to ensure that data were transferred accurately into RevMan for meta-analysis. If the data are found to correspond with the original article, then the authors of relevant papers will be contacted to check the accuracy of the original data.

Publication bias

Publication bias for published versus unpublished work will be conducted by visually reviewing funnel plots, provided sufficient studies have been identified, i.e. 10 studies or more.

Missing data

Missing data or study dropouts will be recorded for each study included in the meta-analysis. The number, proportion of, and reason for, missing data will be reported, where known. Investigators' intention-to-treat analysis will also be reported (where applicable). Where data required to calculate standardised mean difference or risk ratios is missing, attempts will be made to contact the lead author in order to retrieve this data.

Subgroup analysis

If sufficient studies are found and if information is available, we will examine the following moderators for their influence on effect sizes: intervention type (e.g. direct-payment, brokerage etc.); length / intensity of intervention; use of assessment tools (e.g. resource allocation assessment; needs assessment; person-centred planning); disability type; severity of disability (e.g. mild or severe intellectual disability or mild or advanced dementia); gender of participant and other socio-demographic factors; state run or stated funded but privately run; implementation fidelity; level of natural or unpaid support available; size of budget. RevMan will be used to conduct the subgroup analysis. RevMan undertakes a standard test for heterogeneity across subgroup results rather than across individual study results. The approach incorporates an I-squared statistic for subgroup differences. A random effects model will be used. The approach is described by Higgins and Green (2011) in Chapter 9, section [9.6.3.1](#).

Moderator analysis will also be carried out for studies that conducted follow-up data collection (with the follow-up time point as the moderator). Where possible, time points may be collapsed or grouped together to reflect comparable parameters between studies.

Other dependency issues

Some studies may have the data from a single study published in multiple reports or publications. Great care will be taken to identify these scenarios. Multiple articles pertaining to the same study will be reported in Section B of Table 1 and will be collated into one dataset for inclusion in the meta-synthesis. If it is unclear whether the data originates from a single study, clarification will be sought from authors.

Furthermore, if a study reports two different but valid measures of an outcome (e.g. quality of life), we will combine the effect sizes to create a single pairwise comparison. This is achieved by obtaining a mean effect size and standard error for an outcome using robust standard errors that account for statistical dependencies (Hedges, Tipton, & Johnson, 2010).

Where cluster-randomised studies match the inclusion criteria, they will be assessed to determine if the analysis was undertaken correctly. According to Higgins and Green (2011), such studies are commonly analysed as though randomisation occurred at an individual rather than at cluster level. If this is the case, and provided the necessary information is available, a correction will be made. The intraclass correlation coefficient (ICC) may not be available from the original study, but estimates can be identified from similar studies. Once the data have been corrected, they can be entered into RevMan for inclusion in a meta-analysis.

Treatment of Qualitative Research

Meta-synthesis

There are several ways to synthesise qualitative data in systematic reviews including: narrative synthesis; meta-ethnography; realist synthesis; thematic analysis; content analysis and meta-aggregation. A combination of two complementary approaches will be utilised in this review in two stages. 1) A meta-aggregation or meta-synthesis will be conducted in the first instance whereby a comprehensive and systematic search, data appraisal and extraction will be undertaken using standardised tools where appropriate.

2) The second stage will involve the use of thematic analysis to aggregate the findings from several studies. This commonly used approach provides a flexible method of analysis which can be easily interpreted by researchers from different methodological backgrounds. Furthermore, it is standard practice to thematically categorise the findings at this stage of a meta-synthesis. Therefore, a software assisted thematic analysis will further strengthen this

approach, with the explicit recording of the themes and categories in a rigorous way that facilitates transparent reporting (Thomas & Harden, 2008).

Meta-synthesis combines separate elements to form a coherent whole, using a process of logical deduction. A process has been developed to: translate themes or concepts; capture summarised text that illustrates the theme or concept and re-categorise the data to arrive at a synthesis (Pearson, 2004). Therefore, there will be four stages involved in the synthesis of qualitative data:

- Reading (and coding) the studies
- Determining relations
- Translating the studies
- Synthesising translations (Clark, 2015)

Reading and coding the studies

Each study included in the systematic review, having met all the inclusion and exclusion criteria, will be read carefully and in detail. The main study characteristics will be reported in Table 1 (Appendix C). At this stage the second approach will be adopted whereby thematic analysis will be conducted for each individual study in order to identify the main themes reported. Line-by-line coding of the results will be undertaken using MAXQDA, followed by organising the codes into descriptive themes (MAXQDA, 2014; Thomas & Harden, 2008). A subset of qualitative data will be coded by another author; MAXQDA software will be used to test inter-rater reliability. If kappa-coefficient does not fall between 50% and 70% then emerging codes will be discussed with a third party (SMcG).

Determining relations

Having identified the main themes reported in the results of individual studies, relationships between studies will be explored. Common and recurring themes will be categorised, leading to the development of analytical themes (Thomas & Harden, 2008). At this point the CerQual score will also be determined, completing Section I of Table 1 (Appendix C).

Translating the studies

Having read all the studies at least once, each study will be re-read examining similarities and differences between the concepts.

Synthesising translations

The analytical themes which have emerged will have the potential to produce new understanding or conceptual development. The studies will be conceptually folded together, using the concepts from individual studies and the emergent analytical themes as a lens to understand the whole body of work. (Clark, 2015)

Limitations

Despite a rigorous quality assessment of qualitative studies, further potential limitations may apply to synthesising the data. The conclusions drawn may be limited due to a lack of rich primary data (Bearman & Dawson, 2013). Furthermore, specific details may not be provided on the implementation of the intervention, which is the focus of the qualitative research question in this review. However, this will not be known until the studies have been read in detail. Nonetheless, the dual quality assessment of individual studies (i.e. using both CerQual and CASP) and the transparency of the synthesis as proposed within this protocol will ensure that every effort is made by the authors to capture important, in-depth findings not reported in the meta-synthesis. In addition, and as recommended by Bearman and Dawson (2013) the qualitative findings will be presented in as accessible a manner as possible for ease of interpretation. Therefore, details will include how texts were read, how the team negotiated the synthesis, how the analysis was derived and the various checks and balances that were undertaken to ensure the rigor of the analysis. Limitations will be clearly acknowledged and reported without the use of specialised language.

Drawing conclusions

Chandler et al (2012) recommends that when formulating conclusions, only studies that are included in the meta-analysis should be referenced. Therefore, no single study will be heavily relied upon, but rather, every effort will be made to report the synthesised findings in a balanced way. It is anticipated that the findings of this review will provide a clear indication of the effectiveness of personal budgets in improving health and social care outcomes and in so doing, inform future policy and practice decisions. Furthermore, the subgroup analysis should shed some light on what type of model works best for different types of disability or other socio-demographic groupings. Where appropriate, gaps in knowledge will be identified and areas for future research highlighted.

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DECLARATIONS OF INTEREST

This SR will be conducted as part of the lead author’s PhD. A potential conflict of interest may exist since both the lead author (PF) and the personal budgeting initiatives that are the subject of his research, are funded by the same agency (i.e. Genio). However, it is important to note that PF is completing his PhD as part of a prestigious structured doctoral programme in the field of population health/health services research called SPHeRE funded by the Health Research Board in Ireland (www.sphereprogramme.ie). All SPHeRE scholars receive intensive instruction in various methodologies during the course of their first year whilst they are also encouraged to pursue high standards, rigor and objectivity in everything that they do. Furthermore, they are supervised, not only by top health services researchers in the country, but are also supported and guided by an academic panel of senior health services/population health researchers throughout the course of their studies.

Thus, the lead author will strive to be as objective and independent as possible and any conflict of interest will be disclosed in the reporting of the study. All necessary steps will also be taken to avoid any bias that may arise in this respect. SMcG is principal supervisor of PFs' PhD. FK is Director of Research and Evidence in Genio. MF and MH have no conflict of interest.

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ROLES AND RESPONSIBILITIES

Content

Padraic Fleming (PF) is conducting his PhD in the area of personal budgets (under the supervision of SMcG). He has completed a work placement at Genio which funds personal budgeting initiatives in Ireland and has visited a number of personal budgeting projects. PF has familiarised himself with the relevant policy and practice literature in the area of disability and specifically personal budgets. His primary research will involve an evaluation of the development and implementation personal budgeting pilot initiatives in Ireland. PF has also collaborated in published research examining employment guidance services for people with disabilities in Europe.

Mairead Furlong (MF) completed a doctoral fellowship in the field of early intervention for children and families and her previous clinical work involved working with children with educational, behavioural and learning difficulties. She is also currently leading a co-registered Campbell and Cochrane review of interventions for children with mathematical learning disabilities.

Sinead McGilloway (SMcG) has undertaken, supervised and led numerous research projects in applied mental health and social care and she has secured significant research income and published widely in the field of mental health, learning disabilities, early intervention and prevention and palliative/end of life care. SMcG brings considerable content expertise especially in mental health as well as methodological expertise in the conduct of systematic reviews.

Fiona Keogh (FK) has over 20 years' experience in conducting health research in Ireland, in mental health and in the wider disability sector. Most recently, she wrote the report of the Expert Disability Policy Reference Group which was part of the Value for Money Review of Disability Services.(Department of Health, 2012) FK has also worked for the Mental Health Commission, preparing and implementing a Research Strategy for the organisation and was part of the management team that implemented the *Mental Health Act 2001*. She worked as the researcher and writer for the Expert Group on Mental Health Policy and drafted much of the government's current mental health policy *A Vision for Change*. FK previously worked for the Health Research Board as the senior researcher in the Mental Health Division and as the researcher on a comprehensive

evaluation of a community mental health service in West Dublin.

Marian Herson (MH), as part of her Masters, worked in a health service funded not-for-profit organisation which dealt with mental health promotion in young people, and her dissertation focussed on the role of social support and self-esteem in team sports promoting positive mental health.

Tim Stainton's (TS) main interest lies in the area of disability with a particular emphasis on intellectual disability. After a number of years in practice in both BC and Ontario, where he was director of policy and programmes for the Ontario Association for Community Living, he moved to Britain where he completed his doctorate looking at the rights of people with developmental disabilities and individualized funding. He has published numerous books and articles on individualized funding, disability rights, history, ethics and theory. His current research ranges from studying rights based support and service models, individualized funding, ethics and intellectual disability, disability rights and the historical construction of intellectual disability. He is active in the International Association for the Scientific Study of Intellectual Disability and a founding member of their Ethics research group. He is also active in consultation and training on disability related issues internationally. He is a board member of both the BC and Canadian Associations for Community Living. In 2009 he helped to establish the Centre for Inclusion and Citizenship at the School and is currently Director (<http://cic.arts.ubc.ca/>). Tim sit on the Editorial Boards of Australian Social Work, The British Journal on Learning Disabilities, the Journal on Social Inclusion and is a consulting Editor for Intellectual and Developmental Disabilities and frequent reviewer for a range of Journals in Social Work, Social Policy and Disability. He is currently guest editor with Isabel Clare of a special Issue of the Journal of Intellectual Disability Research on Human Rights and intellectual disability.

**Systematic
Review
Methods**

MF is the lead author (or co-author) of three Cochrane/Campbell reviews: (1) parenting programmes for child conduct problems; (2) interventions to improve mathematical outcomes for children with dyscalculia; and (3) home-care 'reablement' services for improving and maintaining functional independence in older adults. Currently, MF, along with SMcG, is involved in the registration of two other Cochrane and Campbell reviews in the fields of palliative care and child mental health respectively. MF was recently elected as the co-chair of the Campbell Social Welfare Group. She is also

	<p>Associate Lecturer with the UK Cochrane Centre and delivers Cochrane training workshops in Ireland. In addition, MF, along with SMcG, are co-founders and directors of PRISM (Promoting research Innovation in Systematic Reviews and Meta-analysis), a research and training/teaching hub set up in Maynooth University to develop capacity and expertise in systematic review methodology for professionals and researchers in Ireland.</p> <p>SMcG is a co-author on the three reviews listed above. She is also involved as a co-author in the registration of two other Cochrane and Campbell reviews in the fields of palliative care and child mental health respectively (see also above for further information).</p> <p>Marian Hernon (MH) has previously participated in Cochrane Collaboration Systematic Review training. MH has been part of a systematic review team on a review titled 'Measurement tools for adherence to non-pharmacological self-management treatment for chronic musculoskeletal conditions: a systematic review'; this review is in press with Archives of Physical Medicine and Rehabilitation. MH has extensive experience in systematic review methodologies including article screening, data extraction, data synthesis and manuscript preparation.</p> <p>PF has participated in Cochrane Collaboration Systematic Review training delivered by the Health Research Board in Dublin and PRISM training in Maynooth University. PF has extensive research skills required for completing a systematic review including: literature searching, data synthesis and analysis and preparing papers for publication.</p>
<p>Statistical Analysis</p>	<p>Both MF and SMcG have previously been authors on completed systematic reviews using meta-analytic techniques, while other reviews are in progress. They also deliver training workshops on systematic reviewing which include the use of statistical methods in meta-analyses. All six researchers are trained in statistical analysis and have attended formal workshops on meta-analytic techniques.</p>
<p>Information Retrieval</p>	<p>All six researchers are knowledgeable in information retrieval and the lead researcher will consult with a social sciences librarian at Maynooth University. During the protocol stage, we will liaise with the information retrieval specialist at Campbell.</p>

EXPECTED TIMEFRAME

Once the protocol is approved, the authors anticipate that a first draft of the completed review will be submitted to the Education Coordinating Group within six months.

PLANS FOR UPDATING THE REVIEW

The authors will examine the review every three years for update.

AUTHORS' RESPONSIBILITIES

By completing this protocol, you accept responsibility for preparing, maintaining, and updating the review in accordance with Campbell Collaboration policy. The Coordinating Group will provide as much support as possible to assist with the preparation of the review.

A draft review must be submitted to the Coordinating Group within two years of protocol acceptance. If drafts are not submitted before the agreed deadlines, or if we are unable to contact you for an extended period, the Coordinating Group has the right to de-register the title or transfer the title to alternative authors. The Coordinating Group also has the right to de-register or transfer the title if it does not meet the standards of the Coordinating Group and/or the Campbell Collaboration.

You accept responsibility for maintaining the review in light of new evidence, comments and criticisms, and other developments, and updating the review every five years, when substantial new evidence becomes available, or, if requested, transferring responsibility for maintaining the review to others as agreed with the Coordinating Group.

Publication in the Campbell Library

The support of the Coordinating Group in preparing your review is conditional upon your agreement to publish the protocol, finished review, and subsequent updates in the Campbell Library. The Campbell Collaboration places no restrictions on publication of the findings of a Campbell systematic review in a more abbreviated form as a journal article either before or after the publication of the monograph version in *Campbell Systematic Reviews*. Some journals, however, have restrictions that preclude publication of findings that have been, or will be, reported elsewhere and authors considering publication in such a journal should be aware of possible conflict with publication of the monograph version in *Campbell Systematic Reviews*. Publication in a journal after publication or in press status in *Campbell Systematic Reviews* should acknowledge the Campbell version and include a citation to it. Note that systematic reviews published in *Campbell Systematic Reviews* and co-registered with the Cochrane Collaboration may have additional requirements or restrictions for co-publication. Review authors accept responsibility for meeting any co-publication requirements.

I understand the commitment required to undertake a Campbell review, and agree to publish in the Campbell Library. Signed on behalf of the authors:

Form completed by: Padraic Fleming

Date: 29/05/2015

**APPENDIX A: SEARCH STRINGS FOR VARIOUS ELECTRONIC
DATABASES / SEARCH ENGINES**

Database	EMBASE (13,848 returns) – Emtree headings and title, abstract
Syntax	'intellectual impairment'/exp OR 'disability'/exp OR handicap OR ((people OR person* OR individ*) NEAR/3 (disabil* OR disable*)):ab,ti OR insanity OR (mental NEAR/1 (instability OR infantilism OR deficiency OR disease OR abnormality OR change OR confusion OR defect* OR disorder* OR disturbance OR illness OR insufficiency)):ab,ti OR (psych* NEAR/1 (disease OR disorder* OR illness OR symptom OR disturbance)):ab,ti AND ('financial management'/exp OR ((budget OR finance* OR fund* OR resource OR money OR income OR purchas* OR broker* OR salary OR capital OR investment OR profit) NEAR/3 (individual* OR person*)):ab,ti) OR 'cash for care':ab,ti OR 'consumer directed care':ab,ti OR 'direct payment':ab,ti OR 'indicative allocation':ab,ti OR 'individual budget':ab,ti OR 'individual service fund':ab,ti OR 'managed account':ab,ti OR 'managed budget':ab,ti OR 'notional budget':ab,ti OR 'personal budget':ab,ti OR 'personal health budget':ab,ti OR personalisation:ab,ti OR 'personalised care':ab,ti OR personalization:ab,ti OR 'person centred':ab,ti OR 'pooled budget':ab,ti OR 'recovery budget':ab,ti OR 'resource allocation system':ab,ti OR 'self-directed assessment':ab,ti OR 'self-directed care':ab,ti OR 'self-directed support':ab,ti OR 'support plan':ab,ti OR 'virtual budget':ab,ti OR 'disability living allowance':ab,ti AND [1985-2015]/py
Database	PsychInfo (11,699 returns) – database heading and title, abstract
Syntax	TI (((((((((((((((DE "Disability Evaluation") OR (DE "Disability Management")) AND (DE "Syndromes" OR DE "Disabled (Attitudes Toward)" OR DE "Intellectual Development Disorder (Attitudes Toward)" OR DE "Dementia" OR DE "AIDS Dementia Complex" OR DE "Dementia with Lewy Bodies" OR DE "Presenile Dementia" OR DE "Semantic Dementia" OR DE "Senile Dementia" OR DE "Vascular Dementia" OR DE "Mental Illness (Attitudes Toward)" OR DE "Physical Disabilities (Attitudes Toward)" OR DE "Sensory Disabilities (Attitudes Toward)")) OR (DE "Disabilities" OR DE "Developmental Disabilities" OR DE "Learning Disabilities" OR DE "Multiple Disabilities" OR DE "Reading Disabilities")) OR (DE "Disorders" OR DE "Adventitious Disorders" OR DE "Atypical Disorders" OR DE "Behavior Disorders" OR DE "Communication Disorders" OR DE "Congenital Disorders"

OR DE "Feeding Disorders" OR DE "Intellectual Development Disorder" OR DE "Learning Disorders" OR DE "Mental Disorders" OR DE "Physical Disorders")) OR (DE "Special Needs")) OR (DE "Disabled (Attitudes Toward)" OR DE "Intellectual Development Disorder (Attitudes Toward)" OR DE "Mental Illness (Attitudes Toward)" OR DE "Physical Disabilities (Attitudes Toward)" OR DE "Sensory Disabilities (Attitudes Toward)")) OR (DE "Brain Disorders" OR DE "Acute Alcoholic Intoxication" OR DE "Anencephaly" OR DE "Aphasia" OR DE "Athetosis" OR DE "Balint's Syndrome" OR DE "Brain Damage" OR DE "Brain Neoplasms" OR DE "Cerebral Palsy" OR DE "Cerebrovascular Accidents" OR DE "Chronic Alcoholic Intoxication" OR DE "Diaschisis" OR DE "Dysexecutive Syndrome" OR DE "Encephalitis" OR DE "Encephalopathies" OR DE "Epilepsy" OR DE "Epileptic Seizures" OR DE "General Paresis" OR DE "Hydrocephalus" OR DE "Intracranial Abscesses" OR DE "Kluver Bucy Syndrome" OR DE "Leukoencephalopathy" OR DE "Microcephaly" OR DE "Organic Brain Syndromes" OR DE "Parkinson's Disease" OR DE "Tay Sachs Disease")) OR (DE "Mental Health" OR DE "Community Mental Health")) OR (DE "Mental Disorders" OR DE "Adjustment Disorders" OR DE "Affective Disorders" OR DE "Alexithymia" OR DE "Anxiety Disorders" OR DE "Autism" OR DE "Chronic Mental Illness" OR DE "Dementia" OR DE "Dissociative Disorders" OR DE "Eating Disorders" OR DE "Elective Mutism" OR DE "Factitious Disorders" OR DE "Gender Identity Disorder" OR DE "Hysteria" OR DE "Impulse Control Disorders" OR DE "Koro" OR DE "Mental Disorders due to General Medical Conditions" OR DE "Neurosis" OR DE "Paraphilias" OR DE "Personality Disorders" OR DE "Pervasive Developmental Disorders" OR DE "Pseudodementia" OR DE "Psychosis" OR DE "Schizoaffective Disorder")) OR (DE "Infantilism")) AND (DE "Costs and Cost Analysis" OR DE "Budgets" OR DE "Health Care Costs")) OR (DE "Finance")) OR (DE "Funding")) OR (DE "Money" OR DE "Resource Allocation" OR DE "Venture Capital")) OR (DE "Health Care Costs")) OR AB (((((((((((((((DE "Disability Evaluation") OR (DE "Disability Management")) AND (DE "Syndromes" OR DE "Disabled (Attitudes Toward)" OR DE "Intellectual Development Disorder (Attitudes Toward)" OR DE "Dementia" OR DE "AIDS Dementia Complex" OR DE "Dementia with Lewy Bodies" OR DE "Presenile Dementia" OR DE "Semantic Dementia" OR DE "Senile Dementia" OR DE "Vascular Dementia" OR DE "Mental Illness (Attitudes Toward)" OR DE "Physical Disabilities (Attitudes Toward)" OR DE "Sensory Disabilities (Attitudes Toward)")) OR (DE "Disabilities" OR DE "Developmental Disabilities" OR DE "Learning Disabilities" OR DE "Multiple Disabilities" OR DE "Reading Disabilities")) OR (DE "Disorders" OR DE "Adventitious Disorders" OR DE "Atypical Disorders" OR DE "Behavior

Disorders" OR DE "Communication Disorders" OR DE "Congenital Disorders" OR DE "Feeding Disorders" OR DE "Intellectual Development Disorder" OR DE "Learning Disorders" OR DE "Mental Disorders" OR DE "Physical Disorders")) OR (DE "Special Needs")) OR (DE "Disabled (Attitudes Toward)" OR DE "Intellectual Development Disorder (Attitudes Toward)" OR DE "Mental Illness (Attitudes Toward)" OR DE "Physical Disabilities (Attitudes Toward)" OR DE "Sensory Disabilities (Attitudes Toward)")) OR (DE "Brain Disorders" OR DE "Acute Alcoholic Intoxication" OR DE "Anencephaly" OR DE "Aphasia" OR DE "Athetosis" OR DE "Balint's Syndrome" OR DE "Brain Damage" OR DE "Brain Neoplasms" OR DE "Cerebral Palsy" OR DE "Cerebrovascular Accidents" OR DE "Chronic Alcoholic Intoxication" OR DE "Diaschisis" OR DE "Dysexecutive Syndrome" OR DE "Encephalitis" OR DE "Encephalopathies" OR DE "Epilepsy" OR DE "Epileptic Seizures" OR DE "General Paresis" OR DE "Hydrocephalus" OR DE "Intracranial Abscesses" OR DE "Kluver Bucy Syndrome" OR DE "Leukoencephalopathy" OR DE "Microcephaly" OR DE "Organic Brain Syndromes" OR DE "Parkinson's Disease" OR DE "Tay Sachs Disease")) OR (DE "Mental Health" OR DE "Community Mental Health")) OR (DE "Mental Disorders" OR DE "Adjustment Disorders" OR DE "Affective Disorders" OR DE "Alexithymia" OR DE "Anxiety Disorders" OR DE "Autism" OR DE "Chronic Mental Illness" OR DE "Dementia" OR DE "Dissociative Disorders" OR DE "Eating Disorders" OR DE "Elective Mutism" OR DE "Factitious Disorders" OR DE "Gender Identity Disorder" OR DE "Hysteria" OR DE "Impulse Control Disorders" OR DE "Koro" OR DE "Mental Disorders due to General Medical Conditions" OR DE "Neurosis" OR DE "Paraphilias" OR DE "Personality Disorders" OR DE "Pervasive Developmental Disorders" OR DE "Pseudodementia" OR DE "Psychosis" OR DE "Schizoaffective Disorder")) OR (DE "Infantilism")) AND (DE "Costs and Cost Analysis" OR DE "Budgets" OR DE "Health Care Costs") OR (DE "Finance")) OR (DE "Funding")) OR (DE "Money" OR DE "Resource Allocation" OR DE "Venture Capital")) OR (DE "Health Care Costs"))

AND

TI (person* OR individ* OR fund* OR financ* OR cash OR pay* OR broker* OR self-direct* OR "Cash for care" OR "consumer directed care" OR "direct payment" OR "indicative allocation" OR "individual budget" OR "individual service fund" OR "managed account" OR "managed budget" OR "notional budget" OR "personal budget" OR "personal health budget" OR personalisation OR "personalised care" OR personalization OR "person centred" OR "pooled budget" OR "recovery budget" OR "resource allocation system" OR "self-

	<p>directed assessment" OR "self-directed care" OR "self-directed support" OR "support plan" OR "virtual budget" OR "disability living allowance") OR AB (person* OR individ* OR fund* OR financ* OR cash OR pay* OR broker* OR self-direct* OR "Cash for care" OR "consumer directed care" OR "direct payment" OR "indicative allocation" OR "individual budget" OR "individual service fund" OR "managed account" OR "managed budget" OR "notional budget" OR "personal budget" OR "personal health budget" OR personalisation OR "personalised care" OR personalization OR "person centred" OR "pooled budget" OR "recovery budget" OR "resource allocation system" OR "self-directed assessment" OR "self-directed care" OR "self-directed support" OR "support plan" OR "virtual budget" OR "disability living allowance")</p>
Database	ASSIA (8,166) – database headings and title, abstract
Syntax	<p>SU.EXACT.EXPLODE("Alcoholic dementia" OR "Alzheimer's disease" OR "Dementia" OR "Lewy body dementia" OR "Multi-infarct dementia" OR "Presenile Alzheimer's disease" OR "Presenile dementia" OR "Semantic dementia" OR "Senile dementia" OR "Subcortical dementia" OR "Vascular dementia") OR (SU.EXACT.EXPLODE("Attention deficit disorder" OR "Attention deficit hyperactivity disorder" OR "Behaviour disorders" OR "Compulsive buying" OR "Compulsive foraging behaviour" OR "Conduct disorders" OR "Disruptive behaviour disorders" OR "Head banging" OR "Oppositional defiant disorder") OR SU.EXACT.EXPLODE("Mental health" OR "Sectioned patients") OR SU.EXACT.EXPLODE("Affective psychoses" OR "Anhedonia" OR "Bipolar affective disorder" OR "Childhood depression" OR "Cycloid psychosis" OR "Death depression" OR "Delusional depression" OR "Depression" OR "Maternal depression" OR "Melancholia" OR "Paranoid states" OR "Parental depression" OR "Paternal depression" OR "Postnatal depression" OR "Refractory depression" OR "Vascular depression") OR SU.EXACT.EXPLODE("Aicardi syndrome" OR "Apraxia" OR "Aspartylglucosaminuria" OR "Blindness" OR "Cri du Chat syndrome" OR "De Lange syndrome" OR "Developmental apraxia" OR "Disability" OR "Down's syndrome" OR "Fragile X syndrome" OR "Functional impairment" OR "Learning disabilities" OR "Night blindness" OR "Nonverbal learning disabilities" OR "Perceptual impairment" OR "Prader-Willi syndrome" OR "Retinopathy of prematurity" OR "Sensory impairment" OR "Verbal disability") OR SU.EXACT.EXPLODE("Acrophobia" OR "Acute stress disorder" OR "Adjustment disorder" OR "Affective disorders" OR "Affective psychoses" OR "Agoraphobia" OR "Akathisia" OR "Alcoholic psychoses" OR "Alexithymia" OR</p>

"Anhedonia" OR "Animal phobias" OR "Anthropophobia" OR "Antisocial personality disorder" OR "Anxiety disorders" OR "Asperger's syndrome" OR "Attachment disorders" OR "Attention deficit disorder" OR "Attention deficit hyperactivity disorder" OR "Autism" OR "Autistic spectrum disorders" OR "Avoidant personality disorders" OR "Behaviour disorders" OR "Bipolar affective disorder" OR "Body dysmorphic disorder" OR "Borderline personality disorder" OR "Briquet's syndrome" OR "Cacodemomania" OR "Capgras syndrome" OR "Catatonia" OR "Cenesthopathy" OR "Character disorders" OR "Childhood depression" OR "Childhood disintegrative disorder" OR "Childhood separation anxiety" OR "Chronic posttraumatic stress disorder" OR "Chronic psychiatric disorders" OR "Chronic schizophrenia" OR "Claustrophobia" OR "Combat disorders" OR "Combat related posttraumatic stress disorder" OR "Communication disorders" OR "Compulsive buying" OR "Compulsive foraging behaviour" OR "Conduct disorders" OR "Confusional states" OR "Conversion disorder" OR "Coprohagia" OR "Cotard's syndrome" OR "Cycloid psychosis" OR "Death depression" OR "Delusional depression" OR "Delusional disorders" OR "Demonomania" OR "Dental phobia" OR "Dependent personality" OR "Depersonalization disorder" OR "Depression" OR "Depressive personality disorders" OR "Disruptive behaviour disorders" OR "Dissociative disorders" OR "Dysmorphophobia" OR "Emotional disorders" OR "Erotophobia" OR "Folie a deux" OR "Fregoli syndrome" OR "Gender identity disorder" OR "Generalized anxiety disorders" OR "Head banging" OR "Heller's syndrome" OR "Histrionic personality disorder" OR "Hypochondriasis" OR "Hypomania" OR "Identity crisis" OR "Impulse control disorders" OR "Infantile autism" OR "Insanity" OR "Kleptomania" OR "Koro" OR "Korsakoff's syndrome" OR "Litigious delusional disorders" OR "Mania" OR "Mass psychogenic illness" OR "Maternal depression" OR "Melancholia" OR "Mental illness" OR "Mood incongruent psychoses" OR "Movement disorders" OR "Multi-impulsive personality disorder" OR "Multiple personality disorder" OR "Narcissistic personality disorder" OR "Neurasthenia" OR "Neuroleptic malignant syndrome" OR "Neuroses" OR "Neuroticism" OR "Nocturnal panic disorder" OR "Obsessive-Compulsive neuroses" OR "Oppositional defiant disorder" OR "Organic mood syndrome" OR "Panic disorders" OR "Paranoia" OR "Paranoid schizophrenia" OR "Paranoid states" OR "Paraphrenia" OR "Parental depression" OR "Passive-Aggressive personality disorder" OR "Paternal depression" OR "Personality disorders" OR "Pervasive developmental disorders" OR "Phobias" OR "Pica" OR "Postabortion syndrome" OR "Postnatal depression" OR "Posttraumatic stress disorder" OR "Psychiatric disorders" OR "Psychogenic aspects" OR "Psychogenic polydipsia" OR "Psychoses" OR "Psychotic mood disorders" OR "Psychoticism" OR "Puerperal psychosis" OR

"Querulous paranoia" OR "Refractory depression" OR "Restlessness" OR "Rett syndrome" OR "Sadistic personality disorder" OR "Schizoaffective disorder" OR "Schizophrenia" OR "Schizophreniform disorder" OR "Schizotypal personality disorders" OR "School phobia" OR "Seasonal affective disorders" OR "Selective mutism" OR "Selfdefeating personality disorder" OR "Separation anxiety" OR "Shared paranoid disorder" OR "Snake phobia" OR "Social phobia" OR "Somatization disorders" OR "Somatoform disorders" OR "Spider phobia" OR "Stage fright" OR "Thought disorder" OR "Transference neuroses" OR "Unipolar disorders" OR "Vascular depression" OR "Weight phobia") OR SU.EXACT.EXPLODE("Asperger's syndrome" OR "Autistic spectrum disorders" OR "Childhood disintegrative disorder" OR "Heller's syndrome" OR "Pervasive developmental disorders" OR "Rett syndrome")) AND (SU.EXACT.EXPLODE("Ancillary relief" OR "Balance of payments" OR "Bankruptcy" OR "Basic income" OR "Basic needs budget" OR "Bonds" OR "Budgets" OR "Business sponsorship" OR "Capital investment" OR "Carbon tax" OR "Charges" OR "Cheques" OR "Citizen's income" OR "Coins" OR "Commodities" OR "Commodity taxation" OR "Consumption tax" OR "Contributions" OR "Corporation income tax" OR "Corporation tax" OR "Council tax" OR "Counterpart funds" OR "Currency" OR "Currency unions" OR "Direct foreign investment" OR "Direct payments" OR "Discounts" OR "Dowries" OR "Earned income tax credit" OR "Earnings" OR "Electronic cash" OR "Entry charges" OR "European Monetary System" OR "Exactions" OR "Excise duties" OR "Expenditure tax" OR "Fair rents" OR "Finance" OR "Fiscal austerity" OR "Fiscal competition" OR "Fiscal equalization" OR "Fiscal imbalance" OR "Fiscal impact" OR "Fiscal policy" OR "Flat rate income tax" OR "Foreign exchange" OR "Foreign investment" OR "Forward markets" OR "Gold standard" OR "Government sponsorship" OR "Housing subsidies" OR "Hypothecated taxation" OR "Income" OR "Income distribution" OR "Income tax" OR "Incomes policy" OR "Indirect taxation" OR "Insolvency" OR "Interest relief" OR "Intergovernmental aid" OR "Investment" OR "Islamic unit trusts" OR "Land tax" OR "Local currency" OR "Local taxation" OR "Lump sums" OR "Marriage payments" OR "Microfinance" OR "Monetary policy" OR "Money" OR "National debt" OR "National income" OR "Offshore finance" OR "Overpayments" OR "Overseas income" OR "Payments" OR "Personal finance" OR "Personal investment" OR "Personal taxation" OR "Pocket money" OR "Poll tax" OR "Pre-tax contributions" OR "Prepayment schemes" OR "Profits tax" OR "Programme aid" OR "Programme budgets" OR "Progressive income tax" OR "Property tax" OR "Protection duties" OR "Public finance" OR "Public investment" OR "Public sector borrowing requirements" OR "Regional tax" OR "Remittances" OR "Rents" OR "Repayments" OR "Retainers" OR "Salaries" OR

	<p>"Savings" OR "Sector investment programmes" OR "Seigniorage revenue" OR "Selfinvestment" OR "Selfpayment" OR "Severance payments" OR "Shares" OR "Short term investment" OR "Single Regeneration Budgets" OR "Single tax" OR "Solvency" OR "Sponsorship" OR "Subsidies" OR "Tariffs" OR "Tax concessions" OR "Tax exemption" OR "Tax subsidies" OR "Taxation" OR "Tithes" OR "Tobin tax" OR "Travellers' cheques" OR "Turnover tax" OR "Unit trusts" OR "Value added tax" OR "Wealth tax") OR "Cash for care" OR "consumer directed care" OR "direct payment" OR "indicative allocation" OR "individual budget" OR "individual service fund" OR "managed account" OR "managed budget" OR "notional budget" OR "personal budget" OR "personal health budget" OR personalisation OR "personalised care" OR personalization OR "person centred" OR "pooled budget" OR "recovery budget" OR "resource allocation system" OR "self-directed assessment" OR "self-directed care" OR "self-directed support" OR "support plan" OR "virtual budget" OR "disability living allowance") OR (ab(disabil* OR disabl* OR insan* OR handicap* OR mental health OR mental* OR infantil* OR disorder OR autis* OR deaf OR blind) AND ab(budget* OR finance* OR fund* OR broker* OR resource* OR money OR income OR purchas* OR salary OR capital OR investment OR cash OR profit) AND ab(individ* OR person* OR self-direct* OR self-determin*)) OR (ti(disabil* OR disabl* OR insan* OR handicap* OR mental health OR mental* OR infantil* OR disorder OR autis* OR dementia OR deaf OR blind) AND ti(budget* OR finance* OR fund* OR broker* OR resource* OR money OR income OR purchas* OR salary OR capital OR investment OR cash OR profit) AND ti(individ* OR person* OR self-direct* OR self-determin*))</p>
Database	Medline First Search (5,571) – mesh heading, title, abstract
Syntax	<p>(mh: Disability and mh: Evaluation) OR mh: Dyslexia OR (mh: Dyslexia, and mh: Acquired) OR (mh: Intellectual and mh: Disability) OR (((mh: International and mh: Classification and mh: of and mh: Functioning, and mh: Disability) and mh: Health) OR (mh: Vision and mh: Disorders) OR (mh: ATR-X and mh: syndrome) OR (((mh: Spastic and mh: Paraplegia and mh: 18, and mh: Autosomal and mh: Recessive) OR (mh: Developmental and mh: Disabilities) OR mh: Epilepsy) OR (mh: Muscular and mh: Diseases) OR (mh: Down and mh: Syndrome) OR (mh: Disabled and mh: Persons) OR ((mh: Health and mh: Services and mh: for and mh: Persons with Disabilities) OR ((mh: Mentally and mh: Disabled and mh: Persons) OR mh: Persons with Hearing and mh: Impairments) OR (mh: Deaf-Blind and mh: Disorders) OR (mh: Mental and mh: Disorders) OR ((mh: Mental and mh: Disorders and mh:</p>

Diagnosed and mh: in and mh: Childhood) OR (mh: Mental and mh: Health) OR ((mh: Mental and mh: Retardation, and mh: X-Linked) OR ((mh: Mentally and mh: Ill and mh: Persons) OR ((mh: Delirium, and mh: Dementia, and mh: Amnestic, and mh: Cognitive and mh: Disorders) OR ((mh: Affective and mh: Disorders, and mh: Psychotic) OR ((mh: Abducens and mh: Nerve and mh: Diseases) OR ((mh: Antisocial and mh: Personality and mh: Disorder) OR (mh: Anxiety and mh: Disorders) OR (mh: Anxiety, and mh: Separation) OR mh: Apraxias) OR (mh: Articulation and mh: Disorders) OR (mh: Asperger and mh: Syndrome) OR (mh: Attention and mh: Deficit) and ((mh: Disruptive and mh: Behavior and mh: Disorders) OR ((mh: Attention and mh: Deficit and mh: Disorder with Hyperactivity) OR ((mh: Auditory and mh: Diseases, and mh: Central) OR (mh: Autistic and mh: Disorder) OR (mh: Bipolar and mh: Disorder) OR ((mh: Child and mh: Behavior and mh: Disorders) OR (mh: Communication and mh: Disorders) OR (mh: Deaf-Blind and mh: Disorders) OR (mh: Depressive and mh: Disorder) OR (mh: Learning and mh: Disorders) OR ((mh: Motor and mh: Skills and mh: Disorders) OR (mh: Movement and mh: Disorders) OR (mh: Psychomotor and mh: Disorders) OR (mh: Psychophysiologic and mh: Disorders) OR (mh: Psychotic and mh: Disorders) OR mh: Schizophrenia) or mh: Deafness) or mh: Blindness)))))))))) or (ti: autis* or ti: disabil* or ti: handicap* or ti: disable* or ti: insan* OR ti: mental* or ti: disorder* or ti: dementia or ti: retard*) or (ab: autis* or ab: disabil* or ab: handicap* or ab: disable* or ab: insan* OR ab: mental* or ab: disorder* or ab: retard*) and (mh: Financial and mh: Management) or (ab: Cash w1 care OR ab: consumer w directed w care OR ab: direct w payment OR ab: indicative w allocation OR ab: individual w budget OR ab: individual w service and ab: fund OR ab: managed w account OR ab: managed w budget OR ab: notional w budget OR ab: personal w budget OR ab: personal w health w budget OR ab: personali?ation OR ab: personali?ed w care OR ab: person w centred OR ab: pooled w budget OR ab: recovery w budget OR ab: resource w allocation w system OR ab: self-directed w assessment OR ab: self-directed w care OR ab: self-directed w support OR ab: support w plan OR ab: virtual w budget OR ab: disability w living w allowance) or (ti: Cash w1 care OR ti: consumer w directed w care OR ti: direct w payment OR ti: indicative w allocation OR ti: individual w budget OR ti: individual w service and ti: fund OR ti: managed w account OR ti: managed w budget OR ti: notional w budget OR ti: personal w budget OR ti: personal w health w budget OR ti: personali?ation OR ti: personali?ed w care OR ti: person w centred OR ti: pooled w budget OR ti: recovery w budget OR ti: resource w allocation w system OR ti: self-directed w assessment OR ti: self-directed w care OR ti: self-directed w support OR ti: support w plan OR ti: virtual w budget OR ti: disability w living w allowance) or (ti: fund* n3

	<p>individual* OR ti: budget* n3 individual* OR ti: financ* n3 individual* OR ti: resourc* n3 individual* OR ti: money n3 individual* OR ti: income n3 individual* OR ti: purchas* n3 individual* OR ti: salary n3 individual* OR ti: capital n3 individual* OR ti: invest* n3 individual* OR ti: profit n3 individual*) OR (ti: fund* n3 person* OR ti: budget* n3 person* OR ti: financ* n3 person* OR ti: resourc* n3 person* OR ti: money n3 person* OR ti: income n3 person* OR ti: purchas* n3 person* OR ti: salary n3 person* OR ti: capital n3 person* OR ti: invest* n3 person* OR ti: profit n3 person*) or (ab: fund* w individual* OR ab: budget* w individual* OR ab: financ* w individual* OR ab: resourc* w individual* OR ab: money w individual* OR ab: income w individual* OR ab: purchas* w individual* OR ab: salary w individual* OR ab: capital w individual* OR ab: invest* w individual* OR ab: profit w individual*) OR (ab: fund* w person* OR ab: budget* w person* OR ab: financ* w person* OR ab: resourc* w person* OR ab: money w person* OR ab: income w person* OR ab: purchas* w person* OR ab: salary w person* OR ab: capital w person* OR ab: invest* w person* OR ab: profit w person*)</p>
Database	SCOPUS (10,441) – title, abstract, keyword
Syntax	<p>TITLE-ABS-KEY (disabil* OR disabl* OR mental OR disorder OR autis* OR deaf OR blind OR dementia) AND TITLE-ABS-KEY (budget* OR finance* OR fund* OR broker* OR resource* OR money OR income OR purchas* OR salary OR capital OR investment OR cash OR profit OR "Cash for care" OR "consumer directed care" OR "direct payment" OR "indicative allocation" OR broker* OR "individual budget" OR "individual service fund" OR "managed account" OR "managed budget" OR "notional budget" OR "personal budget" OR "personal health budget" OR personali?ation OR "personali?ed care" OR "person-cent*" OR "pooled budget" OR "recovery budget" OR "resource allocation system" OR "self-directed assessment" OR "self-directed care" OR "self-directed support" OR "support plan" OR "virtual budget" OR "disability living allowance" OR broker*) AND TITLE-ABS (individ* OR person* OR self-direct* OR self-deter* OR disabil* OR disabl* OR mental OR disorder OR autis* OR dementia OR deaf OR blind W/4 budget OR finance* OR fund* OR resource OR money OR income OR purchas* OR broker* OR salary OR capital OR investment OR profit) AND PUBYEAR > 1984 AND (EXCLUDE (SUBJAREA , "PHAR") OR EXCLUDE (SUBJAREA , "ENGI") OR EXCLUDE (SUBJAREA , "COMP") OR EXCLUDE (SUBJAREA , "AGRI") OR EXCLUDE (SUBJAREA , "ENVI") OR EXCLUDE (</p>

	SUBJAREA , "PHYS") OR EXCLUDE (SUBJAREA , "MATH") OR EXCLUDE (SUBJAREA , "MATE") OR EXCLUDE (SUBJAREA , "EART") OR EXCLUDE (SUBJAREA , "DENT") OR EXCLUDE (SUBJAREA , "CHEM") OR EXCLUDE (SUBJAREA , "CENG") OR EXCLUDE (SUBJAREA , "VETE") OR EXCLUDE (SUBJAREA , "ENER"))
Database	Sociological Abstracts (4, 314) -title, abstract, keyword
Syntax	(ab/ti (SU.EXACT.EXPLODE("Developmental Disabilities") OR SU.EXACT.EXPLODE("Learning Disabilities") OR SU.EXACT.EXPLODE("Disability Recipients")) OR SU.EXACT.EXPLODE("Mentally Retarded") OR SU.EXACT.EXPLODE("Acquired Immune Deficiency Syndrome" OR "Alcoholism" OR "Alzheimer's Disease" OR "Anorexia Nervosa" OR "Arthritis" OR "Attention Deficit Disorder" OR "Blood Diseases" OR "Breast Cancer" OR "Bulimia" OR "Cancer" OR "Cerebral Palsy" OR "Depersonalization" OR "Diabetes" OR "Diseases" OR "Disorders" OR "Eating Disorders" OR "Epilepsy" OR "Heart Diseases" OR "Influenza" OR "Language Disorders" OR "Leprosy" OR "Leukemia" OR "Mental Illness" OR "Obesity" OR "Paranoia" OR "Personality Disorders" OR "Physical Abnormalities" OR "Plague" OR "Poliomyelitis" OR "Psychosis" OR "Schizophrenia" OR "Sociopathic Personality" OR "Tuberculosis" OR "Venereal Diseases")) OR SU.EXACT.EXPLODE("Blind" OR "Congenitally Handicapped" OR "Deaf" OR "Handicapped" OR "Mentally Retarded" OR "Physically Handicapped")) OR SU.EXACT.EXPLODE("Community Mental Health" OR "Mental Health") ab/ti SU.EXACT.EXPLODE("Finance" OR "Public Finance") OR (SU.EXACT.EXPLODE("Money") OR SU.EXACT.EXPLODE("Child Support" OR "Contributions (Donations)" OR "Financial Support" OR "Food Stamps" OR "Grants" OR "Public Support" OR "Social Support" OR "Sponsorship" OR "Subsidies" OR "Support")) OR SU.EXACT.EXPLODE("Allocation" OR "Resource Allocation") OR SU.EXACT.EXPLODE("Income" OR "Profits")) OR (SU.EXACT.EXPLODE("Costs" OR "Health Care Costs" OR "Housing Costs" OR "Rents") OR SU.EXACT.EXPLODE("Benefits" OR "Compensation" OR "Minimum Wage" OR "Pensions" OR "Restitution (Corrections)" OR "Salaries" OR "Wages")) OR SU.EXACT.EXPLODE("Capital")) OR SU.EXACT.EXPLODE("Foreign Investment" OR "Human Capital" OR "Investment")) AND ti(person* OR individ* OR fund* OR financ* OR cash OR pay* OR broker* OR self-direct* OR Cash for care OR consumer directed care OR direct payment OR indicative allocation OR individual budget OR

	individual service fund OR managed account OR managed budget OR notional budget OR personal budget OR personal health budget OR personalization OR personalized care OR personalization OR person centred OR pooled budget OR recovery budget OR resource allocation system OR self-directed assessment OR self-directed care OR self-directed support OR support plan OR virtual budget OR disability living allowance)
Database	Worldwide Political Science Abstracts (1,497) - title, abstract, keyword)
Syntax	(ab/ti (SU.EXACT.EXPLODE("Developmental Disabilities") OR SU.EXACT.EXPLODE("Learning Disabilities") OR SU.EXACT.EXPLODE("Disability Recipients")) OR SU.EXACT.EXPLODE("Mentally Retarded") OR SU.EXACT.EXPLODE("Acquired Immune Deficiency Syndrome" OR "Alcoholism" OR "Alzheimer's Disease" OR "Anorexia Nervosa" OR "Arthritis" OR "Attention Deficit Disorder" OR "Blood Diseases" OR "Breast Cancer" OR "Bulimia" OR "Cancer" OR "Cerebral Palsy" OR "Depersonalization" OR "Diabetes" OR "Diseases" OR "Disorders" OR "Eating Disorders" OR "Epilepsy" OR "Heart Diseases" OR "Influenza" OR "Language Disorders" OR "Leprosy" OR "Leukemia" OR "Mental Illness" OR "Obesity" OR "Paranoia" OR "Personality Disorders" OR "Physical Abnormalities" OR "Plague" OR "Poliomyelitis" OR "Psychosis" OR "Schizophrenia" OR "Sociopathic Personality" OR "Tuberculosis" OR "Venereal Diseases")) OR SU.EXACT.EXPLODE("Blind" OR "Congenitally Handicapped" OR "Deaf" OR "Handicapped" OR "Mentally Retarded" OR "Physically Handicapped")) OR SU.EXACT.EXPLODE("Community Mental Health" OR "Mental Health") ab/ti SU.EXACT.EXPLODE("Finance" OR "Public Finance") OR (SU.EXACT.EXPLODE("Money") OR SU.EXACT.EXPLODE("Child Support" OR "Contributions (Donations)" OR "Financial Support" OR "Food Stamps" OR "Grants" OR "Public Support" OR "Social Support" OR "Sponsorship" OR "Subsidies" OR "Support")) OR SU.EXACT.EXPLODE("Allocation" OR "Resource Allocation") OR SU.EXACT.EXPLODE("Income" OR "Profits")) OR (SU.EXACT.EXPLODE("Costs" OR "Health Care Costs" OR "Housing Costs" OR "Rents") OR SU.EXACT.EXPLODE("Benefits" OR "Compensation" OR "Minimum Wage" OR "Pensions" OR "Restitution (Corrections)" OR "Salaries" OR "Wages")) OR SU.EXACT.EXPLODE("Capital")) OR SU.EXACT.EXPLODE("Foreign Investment" OR "Human Capital" OR "Investment")) AND ti(person* OR individ* OR fund* OR financ* OR cash OR pay* OR broker* OR self-direct* OR Cash for care OR consumer directed care

	OR direct payment OR indicative allocation OR individual budget OR individual service fund OR managed account OR managed budget OR notional budget OR personal budget OR personal health budget OR personalisation OR personalised care OR personalization OR person centred OR pooled budget OR recovery budget OR resource allocation system OR self-directed assessment OR self-directed care OR self-directed support OR support plan OR virtual budget OR disability living allowance)
Database	CINAHL (12,167) – title, abstract, keyword
Syntax	((AB ((MH "Attitude to Disability") OR (MH "Neurobehavioral Manifestations+") OR (MH "Behavioral and Mental Disorders+") OR (MH "Behavior and Behavior Mechanisms+") OR (MH "Disability Evaluation") OR "disabilities" OR (MH "Employee, Disabled+") OR (MH "Community Mental Health Nursing") OR "mental" OR (MH "Mental Health") OR (MH "Health Services for Persons with Disabilities") OR (MH "Mental Health Services+") OR ("Dementia+"))) AND (TX ("personal budget" OR (MH "Health Services Purchasing+") OR (MH "Financial Management+") OR (MH "Financial Support+") OR (MH "Resource Allocation+"))) AND (TI (person* OR individ* OR fund* OR financ* OR cash OR pay* OR self-direct*)) OR (AB("Cash for care" OR "consumer directed care" OR "direct payment" OR "indicative allocation" OR "individual budget" OR "individual service fund" OR "managed account" OR "managed budget" OR "notional budget" OR "personal budget" OR "personal health budget" OR personalisation OR "personalised care" OR personalization OR "person centred" OR "pooled budget" OR "recovery budget" OR "resource allocation system" OR "self-directed assessment" OR "self-directed care" OR "self-directed support" OR "support plan" OR "virtual budget" OR "disability living allowance" OR "Broker*")))) OR ((TI ((MH "Attitude to Disability") OR (MH "Neurobehavioral Manifestations+") OR (MH "Behavioral and Mental Disorders+") OR (MH "Behavior and Behavior Mechanisms+") OR (MH "Disability Evaluation") OR "disabilities" OR (MH "Employee, Disabled+") OR (MH "Community Mental Health Nursing") OR "mental" OR (MH "Mental Health") OR (MH "Health Services for Persons with Disabilities") OR (MH "Mental Health Services+" OR "Dementia+"))) AND (TX ("personal budget" OR (MH "Health Services Purchasing+") OR (MH "Financial Management+") OR (MH "Financial Support+") OR (MH "Resource Allocation+"))) AND (TI (person* OR individ* OR fund* OR financ* OR cash OR pay* OR self-direct*)) OR (TI("Cash for care" OR "consumer directed care" OR "direct payment" OR "indicative allocation" OR "individual budget" OR

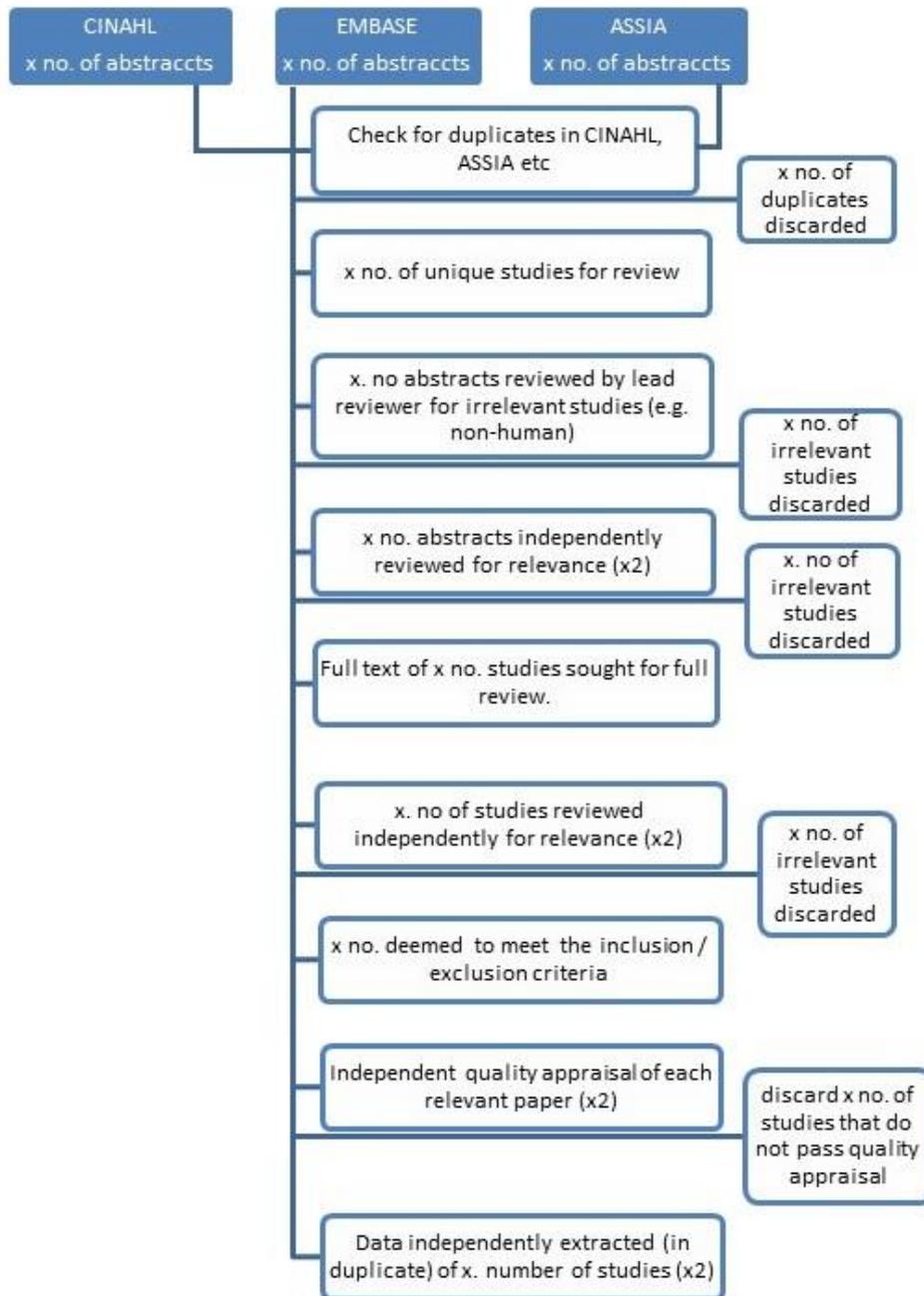
	"individual service fund" OR "managed account" OR "managed budget" OR "notional budget" OR "personal budget" OR "personal health budget" OR personalisation OR "personalised care" OR personalization OR "person centred" OR "pooled budget" OR "recovery budget" OR "resource allocation system" OR "self-directed assessment" OR "self-directed care" OR "self-directed support" OR "support plan" OR "virtual budget" OR "disability living allowance" OR "Broker*")))
Database	EconLit with Full text (1,853) - title, abstract, keyword
Syntax	((AB ((MH "Attitude to Disability") OR (MH "Neurobehavioral Manifestations+") OR (MH "Behavioral and Mental Disorders+") OR (MH "Behavior and Behavior Mechanisms+") OR (MH "Disability Evaluation") OR "disabilities" OR (MH "Employee, Disabled+") OR (MH "Community Mental Health Nursing") OR "mental" OR (MH "Mental Health") OR (MH "Health Services for Persons with Disabilities") OR (MH "Mental Health Services+") OR ("Dementia+"))) AND (TX ("personal budget" OR (MH "Health Services Purchasing+") OR (MH "Financial Management+") OR (MH "Financial Support+") OR (MH "Resource Allocation+"))) AND (TI (person* OR individ* OR fund* OR financ* OR cash OR pay* OR self-direct*)) OR (AB("Cash for care" OR "consumer directed care" OR "direct payment" OR "indicative allocation" OR "individual budget" OR "individual service fund" OR "managed account" OR "managed budget" OR "notional budget" OR "personal budget" OR "personal health budget" OR personalisation OR "personalised care" OR personalization OR "person centred" OR "pooled budget" OR "recovery budget" OR "resource allocation system" OR "self-directed assessment" OR "self-directed care" OR "self-directed support" OR "support plan" OR "virtual budget" OR "disability living allowance" OR "Broker*"))) OR ((TI ((MH "Attitude to Disability") OR (MH "Neurobehavioral Manifestations+") OR (MH "Behavioral and Mental Disorders+") OR (MH "Behavior and Behavior Mechanisms+") OR (MH "Disability Evaluation") OR "disabilities" OR (MH "Employee, Disabled+") OR (MH "Community Mental Health Nursing") OR "mental" OR (MH "Mental Health") OR (MH "Health Services for Persons with Disabilities") OR (MH "Mental Health Services+" OR "Dementia+"))) AND (TX ("personal budget" OR (MH "Health Services Purchasing+") OR (MH "Financial Management+") OR (MH "Financial Support+") OR (MH "Resource Allocation+"))) AND (TI (person* OR individ* OR fund* OR financ* OR cash OR pay* OR self-direct*)) OR (TI("Cash for care" OR "consumer directed care" OR "direct payment" OR "indicative allocation" OR "individual budget" OR

	"individual service fund" OR "managed account" OR "managed budget" OR "notional budget" OR "personal budget" OR "personal health budget" OR personalisation OR "personalised care" OR personalization OR "person centred" OR "pooled budget" OR "recovery budget" OR "resource allocation system" OR "self-directed assessment" OR "self-directed care" OR "self-directed support" OR "support plan" OR "virtual budget" OR "disability living allowance" OR "Broker*")))	
Search Engine	Google Scholar – 6,040	
Syntax	disability disabled mental disorder budget fund cash allocation personalized	
Database	OpenGrey.eu	
Syntax	Disability or disabilities – 2700	“Personal budget” – 17
	Mental – 4196	"individual budget" – 74
	Disorder – 2567	individualized AND disability – 2
	Dementia - 762	individualized AND mental – 2
	Handicap – 1003	personalized AND disability – 0
	Retard - 1380	personalized AND mental – 1
	Blind – 879	personalized AND disorder – 1
	Deaf – 350	budget AND disability – 0
	Impairment - 1049	budget AND mental – 1
	Autism – 520	budget AND disorder – 2
	Autistic - 272	"cash and counselling" – 0
	Personalisation – 61	“consumer directed care” - 0
	Personalization – 75	"direct-payment" OR “direct

	"personalised care" – 21 "personalized care" – 21 "person centered" – 13 "person centred" – 84 "self-directed" – 69	payment" – 31 "personal health budget" – 2 "support plan" - 386
Database	GreyLit	
Syntax	Disability or disabilities – 565 Mental – 1402 Disorder – 983 Dementia - 62 Handicap – 2 Retard - 7 Blind – 14 Deaf – 3 Impairment - 34 Autism – 9 Autistic - 3 Personalisation – 5 Personalization – 1019 "personalised care" – 1 "personalized care" – 21	"Personal budget" – 1 "individual budget" – 3 individualized AND disability – 65 individualized AND mental – 82 personalized AND disability – 235 personalized AND mental – 77 personalized AND disorder – 44 budget AND disability – 37 budget AND mental – 15 budget AND disorder – 14 "cash and counselling" – 9 "consumer directed care" - 2 "direct-payment" OR "direct payment" – 3 "personal health budget" – 2 "support plan" - 5

	<p>"person centered" – 7</p> <p>"person centred" – 2</p> <p>"self-directed" – 3</p>
	<p>Searched separately with zero returns:</p> <p>"indicative allocation"; "individual service fund"; "managed account"; "notional account"; self-determination; "pooled budget"; "recovery budget"; "resource allocation system"; "virtual budget"; "disability living allowance"</p>
Database	Proquest dissertation and Thesis – 8,270
Syntax	<p>ab(disabil* OR disabl* OR insan* OR handicap* OR dementia OR mental health OR mental* OR infantil* OR disorder OR autis* OR deaf OR blind) AND ab(budget* OR finance* OR fund* OR resource* OR money OR income OR purchas* OR salary OR capital OR investment OR cash OR profit) AND ab(individ* OR person* OR self-direct* OR self-determin*)</p> <p>OR</p> <p>ti(disabil* OR disabl* OR insan* OR handicap* OR dementia OR mental health OR mental* OR infantil* OR disorder OR autis* OR deaf OR blind) AND ti(budget* OR finance* OR fund* OR resource* OR money OR income OR purchas* OR salary OR capital OR investment OR cash OR profit) AND ti(individ* OR person* OR self-direct* OR self-determin*)</p>
Search engine	Google
	<p>Google will be searched to identify any relevant conference proceedings in addition to relevant NGOs that may have relevant research unpublished elsewhere.</p> <p>The following terms will be searched:</p> <p>disability disabled mental disorder budget fund cash allocation personalized</p>

**APPENDIX B: FLOW CHART DETAILING STAGES OF SEARCH
PROCESS AND DATA REVIEW**



APPENDIX C: TABLE 1 PILOT SCREENING / DATA EXTRACTION / CODING FORM

Personal Budgeting Interventions to Improve Health and Social Care Outcomes for People with a Disability: A Systematic Review

Study ID: _____ **Coder:** _____ **Date:** _____

APA Citation: _____

Section A: Eligibility Screening Form	Study Name
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Has a state funded personal budgeting intervention been utilised?

- Yes
- Unsure
- No, then STOP!

Is the study population aged over 18 years of age?

- Yes
- Unsure
- No, then STOP!

Does the study population have any form of physical, sensory, intellectual or developmental disability, dementia or mental health problem, disorder or illness?

- Yes
- Unsure

No, then STOP! Has a study design been adopted which collected and analysed empirical data?

- Yes

Unsure

No, then STOP!

Section B: Detail of literature	Study Name
Authors	
Year	
Study linked to multiple reports? If yes, name all reports	
Details of corresponding author	
Country	
Language	
Is the study published or unpublished?	
Publication Source: (Journal Article, Conference Paper, Master /Doctoral Thesis, Organisational/Government Report, Book or Book Chapter or Other)	

Study funding (Gov't / gov't related agency / NGO / Academic Institution / Private company / Employer)	
Is the study quantitative, qualitative or mixed methods?	
Section C: Study summary	Study Name
Aims of the study	
Any further research questions addressed	
Person(s) with disability designed or conducted the research	
Type of services study population availed of prior to personal budget intervention	
Conceptual Framework / Theory used	
Summary of findings (100 words max)	
Section D: Study Design	Study Name

Type of Study		
Systematic Review, RCT, Cohort Study, Case control study, Controlled before and after study, Longitudinal study, Cross-sectional survey, Qualitative study.		
Ethics received		
Sampling / participant recruitment procedure		
Sample size		
Total		
Control		
Intervention		
Response rate / Participation rate		
Section E: Participant descriptors	Study Name	
	Intervention Group	Control Group
Socio-demographic factors:		

Age range

Disability type – Physical, Sensory,
Intellectual, Developmental, Dementia,
Mental or Other

Race / Ethnicity

Sexual orientation

Gender

Religious beliefs

Household income OR High, middle or
low income country

Urban/rural setting

**Section F: Intervention
descriptors**

Study Name

Intervention date and duration

Intervention location

Intervention type

(Direct-Payment, Brokerage, Other)	
Briefly describe intervention	
Residential setting	
Tools used to assist resource allocation (Needs assessment, resource allocation system, person-centered plan, other)	
How much was allocated per person?	
How was money spent? Services, supports, activities etc. (List all reported)	
List all types of supports Paid Natural/Unpaid	
Method of data collection and who collected data (e.g. researcher / service provider / other professional)	

Evidence of implementation fidelity?

Yes, no, unclear (specify)

Section G: Control descriptors	Study Name
Name the control / comparison (as reported)	
Briefly describe the control	
Location of control	
Date and duration of control (if applicable)	
Type of residential setting (Own home, family home, group home, large institution, other)	
Cost of service provision Services, supports, activities etc. provided by service. (List all reported)	
How was money allocated	

<p>Tools used to assist resource allocation</p> <p>(Needs assessment, resource allocation system, person-centered plan, other)</p>	
<p>List all types of supports</p> <p>Paid</p> <p>Natural/Unpaid</p>	
<p>Method of data collection and who collected data (e.g. researcher / service provider / other professional)</p>	
<p>Evidence of implementation fidelity?</p> <p>Yes, no, unclear (specify)</p>	
<p>Section H: Outcomes measures and effect sizes</p>	<p>Study Name</p>
<p>List of outcomes reported</p> <p>QoL</p> <p>Client Satisfaction</p>	

Physical functioning	
Financial data	
Adverse psychological impact	
Reliability of each outcome measure used	
Validity of outcome measure used	
Number of follow-up data-collection points	
Timeframe of data collection points	
Statistical test type	
Appropriateness of statistics	
Yes, no, unclear (specify)	
Means adjusted	
Yes, no, unclear (specify)	
Statistical value (t-test, F-value)	

Degrees of freedom	
Reported effect size and standard error	
Outlier effect size	
Yes, no	
p-value	
N and effect size for each follow up for intervention and control groups (if applicable)	
As treated or intention to treat analysis?	
- N randomised and N analysed in intervention and control groups	
- Per cent missing data in intervention and control groups	
Section I: Quality and Risk of bias scores	Study Name
	Score: (High, Moderate,
	Support for judgement: (Quote, Email communication,

	Low)	Comment)
<p>Selection bias.</p> <p>Random sequence generation</p> <p>Allocation concealment</p>		
<p>Performance bias.</p> <p>Blinding of participants and personnel Assessments should be made for each main outcome (or class of outcomes)</p>		
<p>Detection bias.</p> <p>Blinding of outcome assessment</p> <p>Assessments should be made for each main outcome (or class of outcomes)</p>		
<p>Attrition bias.</p> <p>Incomplete outcome data</p> <p>Assessments should be made for each main outcome (or class of outcomes)</p>		
<p>Reporting bias.</p>		

Selective reporting		
Other bias / limitations.		
Inappropriate influence from funders		
Cross over of between intervention and control		
Other		
	Score: (High, Moderate, Low, Very low)	Explanation of GRADE / CerQual assessment
GRADE		
CerQual		

Table 2: The Cochrane Collaboration’s tool for assessing risk of bias

Domain	Support for judgement	Review authors’ judgement
Selection bias.		
Random sequence generation.	Describe the method used to generate the allocation sequence in sufficient detail to allow an assessment of whether it should produce comparable groups.	Selection bias (biased allocation to interventions) due to inadequate generation of a randomised sequence.
Allocation concealment.	Describe the method used to conceal the allocation sequence in sufficient detail to determine whether intervention allocations could have been foreseen in advance of, or during, enrolment.	Selection bias (biased allocation to interventions) due to inadequate concealment of allocations prior to assignment.
Performance bias.		
Blinding of participants and personnel Assessments should be made for each main outcome (or class of outcomes).	Describe all measures used, if any, to blind study participants and personnel from knowledge of which intervention a participant received. Provide any information relating to whether the intended blinding was effective.	Performance bias due to knowledge of the allocated interventions by participants and personnel during the study.
Detection bias.		
Blinding of outcome assessment Assessments should be made for each main outcome (or class of outcomes).	Describe all measures used, if any, to blind outcome assessors from knowledge of which intervention a participant received. Provide any information relating to whether the intended blinding was effective.	Detection bias due to knowledge of the allocated interventions by outcome assessors.
Attrition bias.		

<p>Incomplete outcome data</p> <p>Assessments should be made for each main outcome (or class of outcomes).</p>	<p>Describe the completeness of outcome data for each main outcome, including attrition and exclusions from the analysis. State whether attrition and exclusions were reported, the numbers in each intervention group (compared with total randomized participants), reasons for attrition/exclusions where reported, and any re-inclusions in analyses performed by the review authors.</p>	<p>Attrition bias due to amount, nature or handling of incomplete outcome data.</p>
<p>Reporting bias.</p>		
<p>Selective reporting.</p>	<p>State how the possibility of selective outcome reporting was examined by the review authors, and what was found.</p>	<p>Reporting bias due to selective outcome reporting.</p>
<p>Other bias.</p>		
<p>Other sources of bias.</p>	<p>State any important concerns about bias not addressed in the other domains in the tool.</p> <p>If particular questions/entries were pre-specified in the review's protocol, responses should be provided for each question/entry.</p>	<p>Bias due to problems not covered elsewhere in the table.</p>

(Table 8.5.a - Higgins & Green, 2011)