



Title Registration for a Systematic Review:

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

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Submitted to the Coordinating Group of:

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TITLE OF THE REVIEW

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

BACKGROUND

Over a billion people – or about 15% of the world’s population - are estimated to live with some form of disability, and the rates of disability are increasing (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 increases in chronic health conditions; people with disabilities have less access to health care services and therefore have more unmet health needs; and there is evidence to suggest people with disabilities have lower life expectancies.

Social care is a term given to describe a range of activities related to individual needs arising from a disability, learning difficulty or mental health problem; for example, 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, and that one way to achieve this is by means of a personal budget. A personal budget places the service user at the centre of the decision making process, 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, while ensuring transparency in the allocation and use of resources. For example, in Ireland, there are several key policy goals enshrined in the Value for Money and Policy Review of Disability Services (Department of Health, 2012) which are influencing strategies in relation to ‘individual needs assessment’. 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, where personal budgets are common, a social care outcomes framework is in place to monitor how well social care services are delivering the outcomes which mean the most to people, and to address any shortcomings (Department of Health, 2013). Monitoring is aided

by tools such as the Adult Social Care Outcomes Toolkit (ASCOT) which has identified eight conceptually distinct attributes: 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 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 quite a lot of administrative duties for the person with a disability.

A brokerage model or ‘managed’ personal budget, on the other hand, provides for a similar amount of freedom for the person with a disability around choice and control of services utilised, but the broker takes responsibility for administrative tasks, and also offers 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. They 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, and influencing the development of payment schemes (Zarb, 1995).

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 account 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).

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. However, these strategic and policy decisions would appear to be evolving based on locally sourced and potentially anecdotal evidence, since there appears to be a lack of high quality experimental studies in the area (Webber, Treacy, Carr, Clark, & Parker, 2014).

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 (Webber et al., 2014). However, in their RCT, Glendinning et al. (2008) reported mixed findings on the impact of a personal budget on health outcomes within their subgroup analyses. Self-reported QoL was higher for the mental health group with a personal budget, than those without, while older people with a personal budget reported lower levels of psychological well-being on the General Health Questionnaire (GHQ-12) than the comparison group. There were also no significant differences between personal budget recipients and control group of people with learning or physical disabilities in relation to QoL and wellbeing outcomes, as well as other measures such as the Adult Social Care Outcomes Toolkit (ASCOT) and self-reported health status (Glendinning et al., 2008). However this study also found that personal budgets impact positively on people's aspirations with respect to what they felt they could achieve in their lives (with the exception of older people); this appeared to be due to the individualised nature of the personal budgets and the extent to which participants felt empowered as a result (Glendinning et al., 2008). 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).

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.

OBJECTIVES

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 any improvements in their health and social care outcomes when compared to a control group of people in receipt of funding from more traditional sources; and (2) to appraise and synthesise the qualitative evidence relating to stakeholder perspectives and experiences of personal budgets, with a particular focus on implementation.

Some key questions include:

- What model of personal budget, e.g. direct payment or brokerage, is most effective at improving health and social care outcomes?
- How is intervention effect linked to length/intensity of intervention?

- Is intervention effect linked to type of presenting disability e.g. physical, sensory, intellectual, developmental or mental disorder?
- Is effect linked to implementation fidelity, e.g. does level of staff knowledge, training and support affect intervention effectiveness?
- Does effect differ depending on the level of support available from non-paid advocates e.g. friends and family?
- Does socio-demographic profile impact on intervention effectiveness, e.g. age, household income, urban/rural setting?
- 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?

EXISTING 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. The search strategy had some major limitations, such as the exclusion of non-English studies and a geographical limitation to 7 countries including: the United States; Australia; Germany; Great Britain; Ireland; Netherlands and New Zealand. Carter Anand et al. acknowledged that the search strategy resulted in a limited evidence base, which precluded the possibility of drawing strong conclusions about the implementation and impact of personal budgets; however, they 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, i.e. 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 (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 were 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. However, methodological shortcomings, for example variation in study design; sample size; and outcomes assessed, limited the extent to which the study findings could be accurately interpreted. This was compounded by considerable variation in the support models assessed 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).

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. The proposed review will: (1) assess the effectiveness of personal budgeting interventions; (2) utilise subgroup analyses to explore how effects may differ by various patient 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 the utilisation of funds from individually allocated resources.

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, since there may be significant variation in how these models are described internationally. For example, Webber et al. (2014) identified: ‘Individual Budgets’; ‘Recovery Budgets’; ‘Personal Budgets’; ‘Direct Payments’; ‘Direct Health Budgets’; and ‘Cash and Counselling’. However, the personal budget must have some fundamental characteristics. It must be provided by the state as financial support for people with a physical, sensory, intellectual, developmental disability or mental health problem. The recipient must be able to freely choose how this money is spent in order to meet their individual needs. They can avail of “brokerage” services or any equivalent service which supports the individual in terms of planning and managing how the money is successfully used over the lifetime of the funding period. They 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). The personal budget can also 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.

For the quantitative element of this review, where a control group exists, their support services can 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, for example, where a service user accesses services through a congregated setting where finances are centralised, but where an individualised plan is used to determine service user needs and preferred activities. The individualisation of planned responses however 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 or other carers, 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 a family member is managing the funds after an individual assessment of need takes place and provided 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.

POPULATION

Inclusion criteria

Adults aged 18 – 65 years 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

Residing in any country

Residing in any type of residential setting (own home, group home, residential care setting, nursing home, hospital, institution)

Exclusion criteria

Adults with dementia since, they do not have choice and control over their daily lives due to the nature of their illness.

Minors under the age of 18 since the decisions around their daily lives are ultimately made by a parent or legal guardian.

While any level of disability and mental health disorders will be included in the review, it is likely that more severe cases will have been excluded from studies due to the necessity for active participation in the planning and management of a personal budget, which may be too challenging for more severe cases (e.g., advanced dementia).

OUTCOMES

Primary Outcomes

- **Quality of Life**, including: physical health; psychological health; social relationships; 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; 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, co-ordination of care, respect shown, information provided, physical and emotional comfort; encouragement, availability of services, cost and administrative burden. The Consumer Assessment of Healthcare Providers (CAHPS) is an example of a set of satisfaction scales which measure various instruments to evaluate 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 Synthesis

- For the qualitative synthesis, outcomes or phenomena of interest will involve the experiences of stakeholders in receiving and implementing a personal budget.

STUDY DESIGNS

Eligible study designs for questions relating directly 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, randomisation may be too difficult since the aim of personal budgets is to increase choice and control, and randomisation limits this option. As such, non-randomised studies (e.g., controlled before and after studies or cohort studies) will be considered in this part of the review. Baseline equivalence of the analytic sample must be demonstrated, or statistical controls must be used in the analysis to control for any between-group differences at baseline. 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. Separate meta-analyses will be conducted for different time points (e.g., up to 3 months follow up, 3–6 month follow up, 6-9 month follow up, 9-12 month follow up and over 1 year follow-up).

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; and documentary analysis. The quality of studies will be assessed using, for example, the Critical Appraisal Skills Programme (CASP) (CASP, 2013). The synthesis will consist of three overlapping stages: (1) line-by-line coding from the result sections of primary studies; (2) organisation of these codes into descriptive themes; and (3) the development of analytical themes (Thomas & Harden, 2008).

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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 Hernon (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.

Systematic review methods:

MF is the lead author (or co-author) of three Cochrane 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 is also Associate Lecturer with the UK Cochrane Centre, Oxford, 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.

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).

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.

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.

Statistical analysis:

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 five researchers are trained in statistical analysis and have attended formal workshops on meta-analytic techniques.

Information retrieval:

All five 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.

POTENTIAL CONFLICTS 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.

FUNDING

PF is a SPHeRE PhD scholar funded by Genio for the duration of his PhD (four years). This review forms part of PFs' PhD.

The review is not funded in any other way, and there are no planned funding applications.

PRELIMINARY TIMEFRAME

Note, if the protocol is not submitted within 12 months of title registration and/or the review is not submitted within 24 months of protocol approval, the review area may be opened up for other authors.

- Date you plan to submit a draft protocol: 31 May 2015
- Date you plan to submit a draft review: 31 May 2016

DECLARATION

Authors' responsibilities

By completing this form, 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.

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Date: 13 January 2015